# **OPERANT LEARNING ACTIVITY PACING**

# **THERAPIST'S MANUAL**

Mélanie Racine, Ph.D., C.Psych.

Warren Nielson, Ph.D., C.Psych.

Mark P. Jensen, Ph.D.

#### INTRODUCTION

This manual was written to support a randomized control trial evaluating the effectiveness of two different activity pacing interventions; one based on operant learning and the other on an energy conservation model of pacing (Nielson, Jensen et Vlaeyen, 2012). Activity pacing is widely used in chronic pain (CP) management both as a stand-alone treatment and as a component of multimodal treatment programs. The present therapist manual focuses on the operant learning approach, which emphasizes the use of positively reinforced activity quotas that are time and/or goal contingent, rather than pain-contingent, using a gradually increasing "activity-rest" cycling approach (Fordyce, 1976).

The development of this manual has been primarily influenced by the work of W.E. Fordyce (1976) as well as a number of other sources describing operant learning inpatient and outpatient treatments for those with chronic pain (Bavinton, Dyer et White, 2004; Burgess et Chalder, 2004; Gil, Ross et Keefe, 1988; Martin, 1980; O'Hara, 1996; Philips et Rachman, 1996; Sanders, 2002; Vlaeyen et al., 2002). More generally, an extensive literature search was also conducted to retrieve articles on operant approaches, and this information also served as the theoretical basis for the development of this treatment manual. This manual is also based on a recent review paper by Nielson et al. (2012) that provided an operational definition of activity pacing and described the components that should be included in both operant learning and energy conservation interventions, based on their theoretical assumptions.

This manual includes a total of 10 group sessions (duration: 2 hours each), two booster sessions at 3 and 6 months post-intervention (duration: 1 hour). The 10 group sessions are held on a weekly basis for the 2 first months, and every 2 weeks for the 3<sup>rd</sup> month. In the research project using this manual, we will include approximately 10 individuals per group and use a closed (vs. open) group format to teach these skills as each session builds on preceding knowledge. Questionnaires will be administered periodically during the intervention to measure both clinical changes and aspects of the treatment process. All sessions have been developed using the same format from session to session in order to make the learning process easier for participants. The contents of each session are as follows:

- Group sessions:
  - Objective
  - Material
  - o Review of homework
  - Teaching session
  - Group Exercise
  - Homework for next week
- Participants' Handouts
- Participants' Homework

This manual has been developed for the general chronic pain population. The examples provided in the therapist manual can be adapted for specific chronic pain conditions. Therapists will notice that we have put an equal emphasis on pain and fatigue. This is because many individuals with chronic pain also experience significant fatigue.

We hope that this therapist manual will serve as a useful clinical resource beyond its purpose in our study. We encourage you to contact us if you have any further questions or are interested in collaborative research on activity pacing.

Sincerely,

**The Activity Pacing Program Team** 

#### **ABOUT THIS MANUAL**

This manual is meant to provide an outline of operant-based activity pacing for experienced therapists. By experienced, we mean health care professionals who have formal training in operant conditioning procedures and have worked with patients who have chronic pain. It is not a "scripted" manual in the sense of following a rigid verbatim treatment. Rather, we provide an outline of content to be covered in each session, very specific goals for each session and homework material to accompany these sessions. Without sufficient background and experience, including the ability to form therapeutic alliances with group members, the procedures described in this manual may not be effective.

With operant-based pacing presenting the concept of "pain behaviors" and the role of learning in chronic pain requires a high degree of clinical acumen. Many patients who have chronic pain have been treated badly by others (including some health professionals) and may already feel "invalidated" and sensitive regarding the legitimacy of their pain. So the process of explaining to them that pain behaviors can be learned is usually quite delicate. Also, for many people, these concepts are fairly abstract and may be hard for them to understand. For example, patients will often interpret this material as suggesting that they are consciously using their pain to somehow manipulate others (e.g., "It sounds like you are telling me that I am acting like I am in pain just to get out of doing the laundry!"). They might think that the program is designed to do more without any regard to how they feel and that it will make people stop being considerate toward them and their needs. Considerable care must be taken to explain these concepts in a clear, accurate and supportive manner. The operant approach is most likely to be properly understood by patients if the therapist presents these concepts by asking them to reflect on and provide examples from their own lives. For example, to help patients understand the role of consequences (reinforcers and punishers) the therapist might ask the group whether they act differently in different social contexts. Do they show their pain the same way at work as they do at home? Do they behave the same way with a close friend as with a stranger? Why do they think they behave differently in different circumstances? Do they consciously decide when to "show" their pain to others or is it sometimes (or often) unintentional? It is critical that patients understand that (1) although pain behaviors (e.g., limping, guarding) may initially serve a function that over time they can cause problems (in relationships, quality of life and physical health) and (2) people do not show pain behaviors "just to get attention". In the final analysis, in order for this treatment to be effective patients must expect that they will benefit from it.

# **OPERANT LEARNING SESSION 1**

**INTRODUCTION TO THE CONCEPT OF PACING: GROUP SESSION** 

#### **SESSION 1 OBJECTIVES**

# At the end of this session the participant will be able to:

- Understand the concept of activity pacing using an operant learning approach
- Identify the extent to which they avoid activities since developing chronic pain in 5 different life domains: chores, exercise/sports, social/leisure activities, mental tasks, work/volunteering/housework
- Use activity analysis to assess their baseline pain and fatigue tolerance as well as their required rest time after an activity

#### **SESSION 1 MATERIALS**

- Name tags
- Activity Pacing group agreement
- Session 1 handouts
- Flipchart

#### INTRODUCTION

# The therapist should introduce him or herself to the group

- Name and experience with the chronic pain condition (e.g. fibromyalgia syndrome (FMS))
- Reason why you have decided to participate in the Activity Pacing (AP) research project
- What does participation in a group intervention entail:
  - o Being active in the activity pacing discussion.
  - Sharing personal experiences about pacing with other participants.
  - Sometimes working in small teams to do exercises.

#### **Icebreaking activity**

- Ask the participants:
  - o Their names.
  - O Where are they from?
  - O What do they expect in coming to this activity pacing group?
  - o Two random facts about themselves?
  - o What is their favorite hobby or pleasurable activity that they are still able to engage in?
- First, ask if there are any volunteers, and if not, use a clockwise approach

# **Activity pacing group agreement (Handout 1)**

 Review the activity pacing agreement with the participants and make sure everyone signs it and returns the copy to you.

#### **TEACHING SESSION 1**

# What is pacing?

- Activity pacing is the regulation of activity level and/or rate in the service of an adaptive goal or goals.
   (Nielson 2012)
- Activities can be very different in nature, most of them require physical (e.g. emptying a dishwasher) or mental (e.g. using your concentration to read a book) effort. They involve many of the things that they feel they need to accomplish throughout their day.
- The present activity pacing program will teach them how to increase their daily life activities using a goal-setting approach related to time or daily goals that they have set in 5 different major life areas: exercising/sports, chores, leisure/social activities, mental tasks and work/volunteering/housework.

# Pacing with chronic pain condition: learning how to increase activity level (Handout 2)

- Briefly explain the chronic pain condition. For example: fibromyalgia syndrome is a neurosensory disorder that is characterized predominantly by symptoms of chronic widespread pain and fatigue.
- It is important that they first understand the difference between acute pain (pain associated with acute injury) and chronic pain (ongoing pain that is not necessarily associated with damage or injury).
- There are two types of chronic pain: chronic pain associated with an initial injury that is now healed (e.g., chronic low back pain) or chronic pain associated with body dysfunction (e.g. fibromyalgia, migraine):
  - Chronic pain following injury: The acute pain associated with an initial injury is an alarm signal from the body. It is a normal physiological response that follows tissue damage and usually resolves when the damaged tissue has healed, or shortly after healing. Pain is generally accompanied by an increase in tiredness and fatigue. However, in about 5% of the cases, even after the body is healed, the pain can persist and become chronic (usually, it is deemed chronic if it lasts more than three months). In this case, the pain sensations no longer communicate anything useful. In fact, these sensations can cause problems if a person's response is to decrease activity or not move a body part because of the pain, because inactivity and lack of movement can contribute to the sensations of pain over time.
  - o <u>Body dysfunction</u>: physiological changes in pain sensitivity as a result of dysfunction in the way that their nervous system processes pain signals (i.e. dysregulation).
- Along this line of thought, it is often natural at the beginning of a chronic pain condition to restrict, diminish
  or stop activities and to rest as much as possible in order to allow the body to heal properly. In the acute
  phase, it was also helpful to accept help from family, relatives, co-workers, etc. Patients may have also
  actively looked for ways to "cure" their pain by searching for support, treatments, medications and services

- from health care professionals. However, despite numerous efforts to get back to normal, in this case, the pain doesn't entirely resolve and becomes chronic.
- Chronic pain is defined as pain that persists beyond the usual healing time (more than 3 months) after an injury or illness, or pain associated with a chronic disorder (ex: arthritis). In chronic pain conditions, pain signals are false alarms in which the pain signals continue to be sent to the brain (1) even though any injuries have healed or (2) as a body dysfunction from the central nervous system. The initial fatigue of the acute phase can also become chronic in the sense that the person experiences profound fatigue that does not improve by resting and gets worse when doing physical or mental activity.
- As the pain and the fatigue shift from acute to chronic, some individuals reduce their daily activities considerably. They may also engage in an "overdoing" pattern in which they constantly push themselves beyond their pain and fatigue tolerance levels. Both of these ways of coping can cause an increase in pain and fatigue. These patterns will be discussed further in session 3.
- It is also important to understand the distinction between actual pain and fatigue, versus pain and fatigue behaviors. Pain and fatigue are what a person feels. It is a subjective experience that only they can fully understand. Pain and fatigue behaviors, on the other hand, are ways in which people show their pain to other people. This includes verbal expressions of pain (such as complaining, asking for help, moaning or sighing), or of fatigue (such as expressing that they are tired, etc). It also includes non-verbal pain behaviors such as grimacing, rubbing or guarding painful body parts, limping, frowning; or fatigue non-verbal behaviors such as sighing, yawning, slouching, etc.
- These outward signs of pain and fatigue that they have developed as their pain has persisted, and can be seen by others will be referred to as pain and fatigue behaviors throughout the program. Verbal and non-verbal pain behaviors are, for the most part, unintentionally learned and can be reinforced by their consequences (e.g., avoidance of difficult tasks, attention, support and caring from others). For example, if a person's husband offers to empty the dishwasher when they see them show pain behaviors when they begin that task, and if this response is positive (note that for some people, offers of help can be more distressing than reassuring), there is an increased likelihood that they will display this behavior again. Similarly, if their partner or spouse sees them rubbing a painful spot they may well offer to give them a massage or some other form of attention, which can reinforce the pain behavior and increase the probability that it will occur in the future if this offer of support is viewed positively or feels good.
- Pain behaviors act as environmental cues, which can elicit support and reinforcement from others.
   Eventually, this learning process can result in increased disability, feelings of inadequacy and worsening of pain and fatigue in the person with chronic pain. It also results in frustration for the partner or spouse, which in the long-term can lead to avoidance of the person with pain, and relationship problems.
- It is especially important to point out that those behaviors are typically learned automatically without the person being aware of their underlying operant conditioning mechanisms. In other words, individuals rarely if ever consciously employ their pain and fatigue behaviors to avoid activities or gain support. The development of pain behaviors is an insidious process that occurs unintentionally and gradually over time.
- Pain and fatigue behaviors that elicit reinforcing responses from others can gradually come under the control
  of those responses. Later on, others may stop their support as they become frustrated, which can result in
  even more pain/fatigue behaviors as the individual responds to the withdrawal of reinforcement. As acute

- pain moves into the chronic phase, it is inevitable that such conditioning occurs as a consequence. Of course, the extent to which these patterns develop varies from person to person.
- Fear-avoidance is a second learning process that is also common in some people with chronic pain. In this case, as pain becomes chronic, individuals can develop a fear of pain. This fear of pain can become more disabling than the pain itself. As time passes, individuals with chronic pain can come to attend more to environmental or physical "threats" or "cues" that signal possible increases in pain and fatigue. They can respond to these threats or cues by avoiding activity. For example, if a person feels a slight pull in their back (i.e., the threat or cue) they may stop doing the activity and go lie down because they are afraid that if they persist, their pain will worsen or they will cause additional physical damage to themselves. In this way, individuals with chronic pain can increasingly avoid participation in activities, including those that previously provided them with pleasure and satisfaction. These patterns will be discussed further in session 5.
- The activity pacing program will help them to become more aware of these learning processes and patterns so that they can gain more conscious control of their responses, reduce their disability, improve their pain and their fatigue (because they are focusing on it less) and improve their relationships. However, it should be made clear that even though they may find that activity pacing helps to reduce their pain and fatigue, the main goal of the program is to increase their activity level and reduce their level of disability. This objective can be achieved by helping them to gradually increase their activity tolerance by using graduated activity goals.
- One very powerful method for being able to do more and hurt less is to couple periods of activity with short rest periods. For this to work well, it is critical that rest periods be goal-contingent and not pain-contingent. This type of pacing will focus on helping them regain control of daily activities that they feel they must do or want to do. This increase in overall activity level will also contribute to improving their general quality of life and will allow them to achieve their goals that they would otherwise not accomplish. Again, although not the primary purpose of this approach, paradoxically, many people who follow these guidelines report a reduction in their pain and fatigue, probably because over time they become more physically active and physically fit and end up paying less attention to their chronic pain condition.

\* 15-MINUTE BREAK \*

# EXERCISE - INDENTIFY "MUST DO" AND "WANT TO DO" ACTIVITIES IN 5 DAILY LIFE DOMAINS

• Have the participants complete this exercise on their own using the following steps. Explain to the participants that some activities can include more than one category. For example, walking the dog could be considered to be a chore, exercise or leisure activity. Thus, one activity can be included in more than one category. However, when the final choice of an activity has been made within a category, it cannot be used elsewhere. It should be reinforced that since they have developed their pain condition there may be some tasks that they are partially or completely avoiding in order to decrease their pain and fatigue levels. Other reasons for task avoidance could be related to the environment "cues" where, for example, other members of the family make decisions for them to not do a particular task (e.g., going to the grocery shopping). Within this matter we will ask them to rate their avoidance between "0 = always avoid" to "10 = never avoid" for each activity.

- <u>Exercising/sports:</u> **(Handout 3)** What are the exercises that they would like to perform or that they are currently performing?
  - Let them complete their list first, specifying that even if they feel they can't do some type of exercise/sport anymore, they should still put them on their list. This is even more important if it is exercise or a sport that they were doing before their pain occurred.
  - After they complete their list, ask them if these exercises (e.g., bicycling, walking, and going to the gym) are easily accessible to them, using this scale: 1 = easily accessible, 2 = fairly accessible, 3 = accessible with difficulty.
  - Ask them to rate the extent to which they avoid each exercise/sports activity because of pain using this scale: 0 = always avoid to 10 = never avoid.
  - Ask them to circle (1) the exercise/sport they avoid the most, but that is easily or fairly accessible; and
     (2) the exercise/sport they slightly avoid (between 7 and 10) and that is easily accessible or at least fairly accessible.
  - Let the group discuss and share the activities they have circled.
- <u>Chores:</u> (Handout 4) Ask them to list in the *Must do* and *Want to do* columns, the chores that they believe they must do (e.g. grocery shopping, doing laundry, preparing dinners) and those that they would like to do (e.g. gardening, helping their children with some school work). They should list the tasks whether or not they do them at the present moment.
  - Ask them to rate how much they avoid doing these chores because of pain: 0 = always avoid to 10 = never avoid.
  - Ask them to look at the chores and then have them pick 3 chores (mark with an X) that meet the following rules
    - (1) a minimum of 1 want to do,
    - (2) 1 completely avoid chore (between 0 and 3); 1 preferably avoid chore (between 4 and 6); and 1 usually don't avoid chore (between 7 and 10).
  - Let the group participants discuss and share the activities they have check-marked with the other members.
- <u>Social/leisure activities:</u> (Handout 5) Ask them to list in the *Must do* and *Want to do* columns, the social or leisure activities that they believe they must do (e.g. attending a dinner with spouse's work colleagues, walking the dog) or that they would like to do (e.g. knitting, playing cards with spouse, going to restaurant with friends). They should also list tasks whether or not they are doing them at the present moment.
  - Ask them to rate how much they avoid doing these social or leisure activities because of pain: 0 =
     "always avoid" to 10 = "never avoid".
  - Ask them to look at the social or leisure activities and then have them pick 3 activities (mark with and
     X) that meet the following rules:
    - (1) a minimum of 2 want to do,
    - (2) 1 completely avoid (between 0 and 3), 1 preferably avoid (between 4 and 6) and 1 usually don't avoid (between 7 and 10) social or leisure activity.
  - Let the group discuss and share the activity they have circled.
- Mental Tasks: (Handout 6) Perhaps some participants will also complain of concentration and memory
  problems, which prevent them from completing sustained mental tasks (or they still do them but find them

much harder). Ask them to list in the *Must do* and *Want to do* columns, the mental tasks that they believe they must do (e.g. calling the insurance company, paying their bills) or that they would like to do (e.g. reading a book, writings email to friends). These should be tasks that they are or are not doing in their daily lives.

- Ask them to rate how much they avoid doing mental tasks: 0 = "always avoid" to 10 = "never avoid".
- Ask them to look at the mental tasks and then have them pick 3 activities (mark with an X) that meet the following rules:
  - (1) a minimum of 1 want to do,
  - (2) 1 completely avoid (between 0 and 3), 1 preferably avoid (between 4 and 6) and 1 usually don't avoid (between 7 and 10) mental task.
- Let the group discuss and share the activities they have circled.
- Work/Volunteering/Housework: (Handout 7) Participants who don't work or volunteer can refer to their chores and mental task lists to pick things they have already circled but not check marked. For those who are working or volunteering, ask them to list in the Must do and Want to do columns, the chores that they believe they must do (e.g. lifting objects, filing folders) or that they would like to do (e.g. supervising school outings, helping in a retirement home). These should be tasks that they are or are not doing in their daily lives.
  - Ask them to rate how much they avoid doing these tasks: 0 = always avoid to 10 = never avoid.
  - Ask them to look at the tasks and then have them pick 3 activities (mark with an X) that meet the following rules:
    - (1) a minimum of 1 want to do,
    - (2) 1 completely avoid (between 0 and 3), 1 preferably avoid (between 4 and 6) and 1 usually don't avoid (between 7 and 10) mental task.
  - Let the group discuss and share the activity they have circled.
- Finally, ask then the participants to write down their final choices, which will serve as their homework assignment.

#### **HOMEWORK**

#### Activity analysis: identify their pain and fatigue baseline and tolerance levels

- Ask them to use the homework sheet along with their weekly calendar to assess their baseline tolerance for activity.
  - First, they have to plan when they are going to try each activity in their list. It is important that they
    adhere as much as possible to their plan in order to start building their routine.
  - Second, they should do the activity until their pain or fatigue increases by 1 or 2 points on the 0 to 10 scales for pain level (0 = no pain and 10 = pain as bad as I can imagine) and fatigue level (0 = no fatigue and 10 = fatigue as bad as I can imagine). They should then write down how much time has passed or how much they have accomplished. For example, they have walked for 10 min or they walked until they have reached the mailbox before the pain or the fatigue started to increase.
  - Third, they should assess how long (e.g. time) they need to rest/relax before the pain or the fatigue goes back down to normal after completing the activity.

It is important that participants understand that this homework is essential even if they are reluctant to work until they feel a pain or fatigue increase (i.e. light increase). This exercise will allow them to know more about their baseline tolerance for activities in order to help them to build a tailored, graded activity program that will suit their needs. Next week they will learn how to build their program by working below their maximum pain and fatigue tolerances (i.e. setting time and goals) and by taking adequate rest time.

# **OPERANT LEARNING SESSION 2**

**ACTIVITY AND REST CYCLING: GROUP SESSION** 

#### **SESSION 2 OBJECTIVES**

# At the end of this session the participant will be able to:

- Understand and apply the activity/rest cycling pattern
- Understand how to use rest, and how to switch while doing activities
- Divide their activities into achievable weekly goals

#### **SESSION 2 MATERIALS**

- Session 2 handouts
- · Flipchart/whiteboard/Digital slides
- Relaxation CDs
- Weekly operant learning group progress chart
  - On a whiteboard (or using a presentation screen) use the following example to construct the group progress chart.
  - o Key: E = exercise/sports, S = Social/leisure activities, W = work/volunteer/housework, C = chores, M = mental tasks, ask participants to put a Y = 'yes' or N = 'no' behind each planned activity indicating whether or not they have met their weekly goals. (coloured dots such as green for 'Yes' and red for 'No' could also be used).
  - Be aware that not all categories are necessary every day so they can leave blank spots in the chart. For example, exercise could be planned for 3 X times per week and therefore isn't included in the chart every day.
  - Because it is important for participants to successfully complete the activities that they choose, it is expected that they will almost always indicate 'Yes' on the shared group chart. If a participant indicates 'No' for an activity for 2 consecutive weeks, the therapist will ask them to return to their previous week's goal. As much as possible, we want to ensure that participants have achievable weekly goals and are successful as they progress to successively more demanding goals.

Miss X		Mon	Tue	Wed	Thu	Fri	Sat	Sun
Week 1	Ε	Υ		Υ		Υ		
	S		Υ		Υ		Υ	
	W	Υ		Υ			Υ	
	С							
	М		Υ		Υ		Υ	
Week 2	Ε	Υ		Υ		Υ		
	S	Υ		Υ	Υ			
	W	Υ		Υ			Υ	
	С							
	M					Υ	Υ	Υ
Week	Е	Y		Υ		N		
	S		Υ				Υ	Υ
	W	Υ		Υ			Υ	
	С	Υ	Υ	Υ	Υ	Υ	N	Υ
	М	Υ		Υ	N			

Mister Y		Mon	Tue	Wed	Thu	Fri	Sat	Sun
Week 1	Е	Υ				Υ		
	S	Υ	Υ		Υ		Υ	Υ
	W	Υ	Υ	Υ	Υ	Υ		
	С	Υ		Υ	Υ		Υ	
	М	Υ	Υ	Υ	Υ	Υ		Υ
Week 2	Ε	Υ				Υ		
	S		Υ		Υ	Υ	Υ	Υ
	W	Υ	Υ	Υ	Υ	Υ		
	С	Υ	Υ	Υ	Υ	Υ		Υ
	M	Υ	Υ	Υ		Υ		Υ
Week	Ε	Υ				Υ		
	S	Υ	Υ	Υ	Υ			Υ
	W	Υ	Υ	Υ	Υ	Υ		
	С	Υ		Υ				Υ
	М	Υ	Υ	Υ	Υ	Υ		Υ

#### SESSION 1 HOMEWORK: FEEDBACK AND DISCUSSION

## Introduce the weekly group activity pacing chart to the participants:

- When participants arrive, ask them whether they have completed the activities ('Yes' or 'No') within each of the 5 life domains they previously selected in order to set their baselines.
- Explain to the group participants that the chart is based on an honor system. Highlight that they won't be
  judged if they did not achieve some of their weekly goals. It is very important for the therapist to know
  whether or not they have completed their goals so that they can provide additional guidance that will help
  them achieve the goals for the subsequent weeks.
- Last week's homework was about discovering their baseline tolerance levels when doing activities that they tend to avoid (between 0 and 3 on the avoidance scale) as well as those that they slightly avoid (between 7 and 10).
  - o How did their plan go in general?
  - How long were they able to persist with the activities that they strongly avoid before pain and fatigue occurred? How long did they need to rest after completing those activities?
  - o Did they feel satisfied with themselves for having completed activities that they previously avoided?
  - o How long were they able to persist with the activities that they *slightly* avoid before pain and fatigue occurred? How long did they need to rest afterwards? Did they find it easier to do the activities that they *slightly* avoid than those that they *strongly* avoid?
- For those who did not meet homework goals in one or more life domains, ask what happened in an empathic manner so that they don't feel punished by your inquiries. As you might expect, it is important to be curious and interested rather than judgmental. If a participant indicates that their pain and the fatigue stopped them from completing the task (e.g., negative reinforcement), explain the importance of being proactive if they want to achieve their goals. Ask them whether or not their goal was set too high.
- For example, a participant might say "I wasn't able to walk the dog outside as I had planned, because I was in too much pain". You could reframe this sentence by saying as "Maybe your goal was set a little too high. How do you think it would work if you just walk your dog to the end of your street and back? " (distance-based

quota). Alternatively, you could ask: "How long do you think you could walk your dog before you might choose to stop because of pain?" (time-based quota). You may also want to ask them how confident they feel in their ability to achieve this revised goal (0-10), and then, if the rating is less than « 10 », ask, « What would it take to increase your confidence from \_\_\_\_ (the number they said) to \_\_\_\_ [the number they said + 2, or « 10 » if the number they said was « 9 »). If the participant did not complete their homework by lack of motivation, ask them about the reasons that they decided to participate in the pacing program. Also highlight that changing habits is always the most difficult at the beginning and that it will get easier as they get used to noticing, and that their progress will motivate them.

#### **TEACHING SESSION 2**

# **Settings ground rules**<sup>1</sup> (Handout 8)

- Explain to the group participants that in order to improve the quality of their lives, they need to focus less on their pain and fatigue levels. Tell them that paradoxically, as they do this more and more, they will end up experiencing a decrease in their pain, just like « You do not feel the sensations of your shirt collar against your neck, until I draw your attention to it ». We experience what we pay attention to.
- Within the group context, when participants talk about their pain and fatigue or when they will display pain
  and fatigue behaviors, the therapist should not respond. The therapist should ignore all negative comments,
  complaints and behaviors related to pain and fatigue.
- Ask them to discuss why the therapist would respond in this way (elicit something along the lines of, « Because the therapist cares, and wants us to hurt less »). Then ask them if they really disliked someone and wanted them to suffer more, how would they respond if that person said they had injured themselves and were feeling pain (elicit something along the lines of, « I would ask them to talk about and describe their pain in more detail, to increase their focus on the pain, and thereby increase their experience of pain »).
- Explain that the underlying concept is to 'unlearn' their learned pain and fatigue behaviors, as was discussed in session 1. Highlight that by not tending to these behaviors, they will focus less on pain and fatigue and more on positive experiences, and feel better as a result.
- The idea is not to withdraw support but to redirect it in a way that reinforces positive pacing behaviors. The
  therapist should explain that they will provide empathy and support to participants, with a focus on helping
  them to achieve their personal goals.
- The therapist should encourage participants to apply the same rules when they interact with each other (e.g., at breaks, during group exercises). They will benefit from this approach because it will help all group members feel positive about the changes they are making and prevent the sessions from degenerating into 'pity parties'. These rules can also be expanded to their interactions with their families and friends. This idea will be addressed in a later session.

<sup>&</sup>lt;sup>1</sup> It is important for therapists to be comfortable with withdrawing attention and support for pain and fatigue behaviors.

# **Activity and rest cycling (Handout 9)**

- The activity and rest cycling principle will help them to better understand how they should manage their daily activities and adequately distribute their tasks over the entire week.
- The major goal is to break the pain/fatigue contingent activity cycle by making activity levels contingent on time or quotas instead of pain and/or fatigue.
- They will learn how to do moderate activity by working at 60% of their baseline pain and fatigue tolerance and by increasing these activities by 5-10% every week. The activity period will be coupled with a limited rest period according to their baseline rest time. The rest period will also be reduced every week in order to be more active during the day. A full day is considered to be about 14-16 waking hours. During that time, participants would alternate between their different activities/tasks and/or limited rest. Note that individuals usually engage in more sedentary activities toward the end of the day.
- Rest periods always have to be time-related. They can be taken at completion of a quota, after a predetermined time period, or at set times during an activity. For example, one participant might decide to iron 3 pieces of clothes (quotas) and then take a 5 minute rest before returning to ironing another 3 pieces, and so on. Another participant could decide to go grocery shopping and to take a 15-minute break (set time) after unpacking the groceries before moving on to another activity. The plan is for participants to be moderately active most of their day. Emphasize that all participants should take all of their planned rest periods and rest for that entire time.
- Switching activities that utilize another group of muscles, or switching from a mentally demanding task to a physically demanding task can also be related to time or quotas. Rest times have to be determined in advance. For example, alternating between folding clothes for 10 minutes, and ironing 3 pieces. Task switching, like rest, has to be determined in advance (i.e., planned) within their weekly goals so that it doesn't serve the purpose of pain or fatigue avoidance but rather to help them to gradually increase their activity level.
- Encourage the group participants to use this strategy for every activity that they are doing even if it is not listed as one of their homework goals.
- Highlight that you understand that although this is a completely different way of doing things, after a few
  weeks they will become quite comfortable with it. They will then discover that they are able to achieve their
  goals, which should be rewarding for them, especially when they see that they are able to accomplish more
  than they had previously thought.

\* 15-MINUTE BREAK \*

#### **TEACHING SESSION 2**

#### **How to rest (Handout 10)**

- As mentioned before, activities should be combined with adequate but limited rest times in order to pace effectively.
- Rest should involve things that are not too physically or mentally demanding. Rest breaks serve the purpose of providing a break to the participants after completing tasks, or in-between periods of sustained effort.
- Everyone prefers some specific types of rest over others. Each participant should choose the ways in which they would like to rest, based on what they consider enjoyable.
- There are many ways to rest when taking breaks, such as:
  - Enjoying a cup of tea,
  - Deep breathing exercises,
  - Relaxation techniques,
  - o Stretching,
  - Sitting in the backyard,
  - o Eating a snack,
  - Lying down for a few minutes,
  - o Etc.
- It is important that rest periods be time-limited (i.e., in minutes) and that they are planned prior to engaging in an activity. Respecting these time limits and then moving on to the next activity is essential in benefiting from the treatment, and achieving their goals.
- Rest time should occur after they have accomplished something in their activity list (i.e., should be goal
  contingent). It is important for them to reward themselves for their accomplishments. In session 3 they will
  also learn other ways that they can positively reinforce themselves when they meet their daily and weekly
  goals.

# **How to rest by switching (Handout 11)**

- Sometimes it is not possible for participants to take a rest period after an activity, for example when they are working. Switching is a useful alternative to rest and will also allow them to manage their activity level.
- Switching means stopping an activity after a pre-determined amount of time (e.g., 15 min of working at a computer) or quotas (e.g., after answering 5 e-mails). Switching involves other groups of muscles or moving from a physical to a mental task (e.g., from walking to making a phone call).
- This method of switching tasks can be done over a longer time interval (e.g., a day), so that it enables participants to achieve their daily goals by alternating tasks (e.g., 20 files and 9 phone calls per day)
- Switching also helps the participants to rest from the previous task (if the previous task was more demanding), and alternating between more demanding tasks and less demanding ones can help them to manage their activity levels.

## How to break task into achievable pieces (Handout 12)

- When planning their weekly goals, participants should consider how their activities could be broken into smaller pieces. For example, 'doing the dishes' implies that the person will do a series of sub-tasks such as filling the dishwasher, scrubbing the pots, hand washing any dishes that cannot go in the dishwasher, doing any hand-drying that is necessary, and cleaning up.
- Each of these sub-tasks or 'pieces' has to be achievable by balancing activity with rest or task switching during and after the task so that the overall goal (e.g. washing the dishes) will be attained.
- Some activities could be divided into pieces throughout an entire day or could even be distributed over 2-3 days. For example, gardening might require shopping, weeding, planting, watering, pruning, etc.
- When breaking tasks into pieces, participants must set their activity quotas and their time-based rest periods (or task switching), before engaging in the activity to ensure that they are goal contingent rather than pain or fatigue contingent.

# How to speed up (Handout 13)

- Explain to participants that by using activity/rest cycling and dividing their activities into manageable pieces they will eventually be able to increase the speed at which they do their tasks.
- Increasing speed involves building their tolerance level up every week. By maintaining moderate activity levels and slowly increasing their speed, they will be able to achieve more during the day.
- To speed up, they will also need to set new quantity or time-based quotas when planning their weekly activity goals. These must be realistic in order to ensure success.
- It is assumed that speeding up activity completion will be rewarding for the participants, since they will achieve their goals in shorter periods of time (or get more done in the same amount of time).

#### **TEACHING SESSION 2**

#### **Building weekly goals**

- It is important that participants experience success when trying to achieve the goals they have set within their 5 life domains. Use Sarah's example (below) to help the participants understand how to develop their own weekly goals.
- Last week's homework was about establishing their baseline levels in order to identify a starting point from which to increase their goals.
- Explain to the participants that they will start to work at 60% of their baseline level when it is feasible (e.g., bicycling, vacuuming, writing e-mails)
- When the participants have to complete entire tasks (e.g., doing filing at work, or helping their daughter with homework), their success will be related to gradually diminishing the number and length of their rest breaks and switching tasks so that they are able to achieve their goals.

Starting with their individual baseline, goals will be split into 5 achievable weekly pieces, which will gradually
increase over the next few weeks according to the therapist's and their own judgment. Everyone has
different goals and will start at a different place. It is important that participants don't judge or compare
themselves with each other. Rather they should be encouraged to motivate each other by recognizing their
successes and their weekly progress.

# Sarah's example:

# **Exercise/sports**

# 1. Bicycling 30 min once a week (usually avoid)

Week 1 (Baseline): 5min, pain increase, 20 min rest to get back to normal pain and fatigue levels.

Week 2: 3 min bicycling and 20 min rest

Week 3: 4 min bicycling and 19 min rest

Week 4: 5 min bicycling and 18 min rest

Week 5: 6 min bicycling and 17 min rest

## 2. Walking 30 min twice a week (slightly avoid)

Week 1 (Baseline): 20 min, pain increase, 15 min rest

Week 2: 12 min walking and 15 min rest, once a week

Week 3: 15 min walking and 14 min rest, once a week

Week 4: 12 min walking and 13 min rest, twice a week

Week 5: 15 min walking and 12 min rest, twice a week

## Social/leisure activities

# 1. Talking on the phone 30 min altogether with a minimum of two friends or relatives per week (usually avoids doing this)

**Week 1 (Baseline):** talked with mother 10 min, started feeling tired, 10 min to get back to normal pain and fatigue levels. Realized that it is more the social isolation since she has pain that makes her avoid the activity.

Week 2: 10 min talking with one friend, rest 10 minutes

Week 3: 12 min talking with two friends, rest 9 minutes

Week 4: 14 min talking with two friends, rest 8 minutes

Week 5: 16 min talking with two friends, rest 7 minutes

# 2. Knitting for 30 min every day to finish my daughter's skirt (not avoid)

Week 1 (Baseline): 30 rows, pain start, 10 minutes to get back to normal

Week 2: Knitting 9 rows, 5 min break, and another 9 rows

Week 3: Knitting 10 rows, 5 min break, and another 10 rows

Week 4: Knitting 11 rows, 5 min break, and another 11 rows

Week 5: Knitting 12 rows, 5 min break, and another 12 rows

# 3. Going outside with the spouse for 1 hour, 2 times a week to chat with him (slightly avoid)

Week 1 (Baseline): 30 min, feel tired and exhausted, rest one hour in front of the TV to get back to normal

Week 2: going outside 15 min twice a week, rest 1 hours

Week 3: going outside 20 min twice a week, rest 50 minutes

Week 4: going outside 25 min twice a week, rest 40 minutes

Week 5: going outside 30 min twice a week, rest 30 minutes

**Work/volunteer/housework:** Sarah works part time (3 days a week) as a dental receptionist, there are some task she would like to avoid but doesn't because she is the only receptionist in the office. She usually meets her work goals with difficulty. She knows she could be more productive. She is at work so switching is required because she is usually unable to take a break between tasks.

# 1. Filing, 2. Complete forms for insurance companies, 3. Call back patients for tomorrow's appointments, and answer their questions (not avoid)

Week 1 (Baseline): 1. Filling: 30 min, pain increase, can't take rest, 2. Complete 5 insurance company forms, fatigue and pain increase, take lunch break, 3. Call every patient who has an appointment, question or needs a reminder for 1 hour, feel pain and exhaustion, leave work, lie on the couch all evening

**Week 2:** File for 10 min, rest 5 min, complete 3 insurance company forms, take 15 min break, make 2 phone calls and start over until lunch break

**Week 3:** File for 12 min, rest 4 min, complete 4 insurance company forms, take 5 min break, make 3 phone calls and start over until lunch break

**Week 4:** File for 14 min, rest 3 min, complete 5 insurance company forms, take 15 min break, make 4 phone calls and start over until lunch break

**Week 5:** File for 16 min, rest 2 min, complete 6 insurance company forms, take 15 min break, make 5 phone calls and start over until lunch break

#### Chores

# 1. Vacuuming 5 rooms per week (slightly avoid)

Week 1 (Baseline): vacuum living room, pain and fatigue increase, rest for 1 hour to get back to normal pain and fatigue levels

Week 2: do half of a room, 45 min rest, 2 times a week (1 room done)

Week 3: do half of a room, 40 min rest, 4 times a week (2 rooms done)

Week 4: do half of a room, 30 min break, the other half, 30 min rest, 4 times a week (4 rooms done)

Week 5: do half of a room, 25 min break, the other half, 25 min rest, 4 times a week (4 rooms done)

# 2. Cooking (usually avoid)

**Week 1 (Baseline):** 15 min of cutting vegetables, pain increase, rest 30 min to get back to normal pain and fatigue levels

**Week 2:** 10 min preparing meals, switch to set the kitchen table, rest 15 min, 10 min preparing meals, and spouse finishes the rest.

**Week 3:** 12 min preparing meals, switch to set the kitchen table, rest 15 min, 12 min preparing meals, and spouse finishes the rest.

**Week 4:** 12 min preparing meals, switch to set the kitchen table, rest 12 min, 12 min preparing meals, and spouse finishes the rest.

**Week 5:** 14 min preparing meals, switch to set the kitchen table, rest 12 min, 14 min preparing meals, and spouse finishes the rest.

# 3. Washing dishes every day until nothing left on the counter (slightly avoid)

Week 1 (Baseline): fill the dishwasher, pain increase, rest for 30 min to get back to normal pain and fatigue levels

Week 2: fill half of the dishwasher, rest for 30 min, do the other half, rest for 30 min

**Week 3:** fill half of the dishwasher, rest for 25 min, do the other half, rest for 25 min, scrub pots and pans for 10 min, rest for 25 min

**Week 4:** fill half of the dishwasher, rest for 20 min, do the other half, rest for 20 min, scrub pots and pans for 12 min, rest for 20 min

**Week 5:** fill half of the dishwasher, rest for 15 min, do the other half, rest for 15 min, scrub pots and pans for 12 min, rest for 15 min, finish dishes if any left

#### Mental tasks

# 1. Writing email for 30 min per week to relatives in Florida (usually avoid)

**Week 1 (Baseline):** write email for 40 min, feel mentally exhausted by trying to remember what interesting things happened in the last 6 months, since she doesn't write on a regular basis. Rest for an hour and a half.

**Week 2:** write email for 18 min, use activity pacing sheet to have ideas of what to say about the things she has accomplished, take 1 hour break

**Week 3:** write email for 20 min, use activity pacing sheet to have idea of what to say about the things she has accomplished, take 45 min break

**Week 4:** write email for 22 min, use activity pacing sheet to have idea of what to say about the things she has accomplished, take 45 min break

**Week 5:** write email for 24 min, use activity pacing sheet to have idea of what to say about the things she has accomplished, take 30 min break

## 2. Doing 30 min of Sudoku twice a week (not avoid)

Week 1 (Baseline): half of a Sudoku puzzle (around 20 min) and feel tired and can't concentrate anymore, need 15 min rest to get back to normal

Week 2: 12 min of Sudoku, 15 min break, 2 times a week

Week 3: 13 min of Sudoku, 13 min break, 2 times a week

Week 4: 14 min of Sudoku, 11 min break, 2 times a week

Week 5: 15 min of Sudoku, 9 min break, 2 times a week

## 3. Helping daughter with homework (not avoid) for 1 hour

Week 1 (Baseline): maintain 1 hour, feel pain and fatigue, take the rest of the evening to get back to normal pain and fatigue levels (around 2 hours). Her daughter prefers to do a straight hour to get rid of her homework

Week 2: 30 min homework before dinner, 30 min homework after dinner, one hour break

Week 3: 30 min homework before dinner, 30 min homework after dinner, 50 min break

Week 4: 45 min homework before dinner, 15 min homework after dinner, 40 min break

Week 5: 45 min homework before dinner, 15 min homework after dinner, 30 min break

### **INDVIDUAL EXERCISE – BUILDING WEEKLY GOALS SHEET (Handout 14)**

- Explain to the group participants that they can build their own plan using the activities they have chosen in session 1. Highlight that Sarah's example is about someone fairly functional, in order to give them ideas of how to build their plan. But it is just an example and is not meant to be used as a 'yardstick' for judging their own activity tolerances.
- Remind them that the most important point is that their weekly goals should be easily achievable. Part of making them achievable is to think about how realistic it is to accomplish each goal in the context of the whole activity list on their weekly schedule. For example, they might want to start slowly with the amount of time that they allow themselves for three weekly chores. This limit might seem reasonable if they are working and not doing much when they get home because other family members have been taking care of most chores since they have developed a chronic pain condition. For some participants, doing the dishes, folding the laundry and vacuuming the living room once a week for 15 min each is a huge step to take.
- Allow them a period of 30 min to complete their goal plan. Check on them individually to make sure they are building a realistic plan and help them if needed.<sup>2</sup>

<sup>2</sup> Note that participants will mostly be 'underdoers' but that the group may also include some 'overdoers'. The former will need to increase and the latter decrease their activity level. This distinction will be discussed in more detail in Session 3.

 Bring the group back together and ask each member to share with the group what they intend to include in their goals for week 1. Reinforce and encourage the group with regard to completion of their week 1 goals. If you find that a participant sets their goals unrealistically high (or too low), help them select a lower or higher starting goal.

#### **HOMEWORK**

#### **ACHIEVING THEIR WEEKLY ACTIVITY GOALS**

- Ask them to use their handout along with their weekly calendar to assess their baseline tolerance for activity.
  - o First, have them plan when they are going to do each activity on their list. It is important that they adhere as much as possible to their plan in order to achieve their goals.
  - Second, they should continue their activities even when they feel an increase of condition-related<sup>3</sup> pain and fatigue while doing them.
  - Third, they should always take their pre-planned rest periods (but not extend them!) irrespective of pain and fatigue.
- It is important that participants understand that adhering to their homework plan is essential, even if they are reluctant to continue activities when they feel a pain or fatigue increase. This exercise will allow them to gradually achieve their goals and reduce their disability level by pacing (setting time-based activities and quotas as well as adequate rest periods).
- Use Sarah's example below to show them how to do their homework.

<sup>&</sup>lt;sup>3</sup> Most participants will be able to distinguish between their usual pain and any new or unusual pain experiences. The intention here is to continue activities in spite of usual pain or fatigue. If they experience a new pain that is inconsistent with their condition, they should be asked to consult a physician.

# Sarah's week 1 homework example:

Exercises/sports	Chores
1. 3 min bicycling and 20 min rest	1. do half of a room, 45 min rest, 2 times a week (1 room done)
2. 3 min bicycling and 20 min rest	<b>2.</b> 10 min preparing meals, switch to set the kitchen table, rest 15 min, 10 min preparing meals, and spouse finishes the rest.
Social/leisure activities	<b>3.</b> fill half of the dishwasher, rest for 30 min, do the other half, rest for 30 min
1. 10 min talking with one friend, with 10 min rest	Mental tasks
2. Knitting 9 rows, taking 5 min break and knitting another 9 rows	1. write email for 18 min, use sheet to have ideas of what to say about the things she accomplished, take 1 hour break
3. Going outside 15 min twice a week, and rest 1 hour	2. 12 min of Sudoku, 15 min break, 2 times a week
Work/volunteer/housework	<b>3.</b> 30 min homework before dinner, 30 min homework after dinner, one hour break
1. File for 10 min, rest 5 min, complete 3 insurance company forms, take 15 min break, make 2 phone calls and start over until lunch break	

# **SARAH'S ACTIVITY PACING DIARY - WEEK 1: MONDAY**

Monday	Type of activity (Goals)	Goals achieved?	Rest time taken?
D.C. avering		(yes, no)	(yes, no)
Morning			
6:00			
7:00			
8:00	Work	Υ	Υ
9:00	Work	Υ	Υ
10:00	Work	Υ	Υ
Lunch			
11:00	Work	Υ	Υ
12:00	Work	Υ	Υ
13:00	Work	Υ	Υ
14:00	Work	Υ	Υ
Afternoon			
15:00	Work	Υ	Υ
16:00	Work	Υ	Υ
17:00	Homework with daughter	Υ	Υ
18:00			
Evening			
19:00	Dishwasher	Υ	Υ
20:00	Knitting	Υ	Υ
21:00			
22:00			
23:00			
24:00			



# **OPERANT LEARNING SESSION 3**

OVER-DOING, UNDER-DOING AND REINFORCEMENT: GROUP SESSION

#### **SESSION 3 OBJECTIVES**

#### At the end of this session the participant will be able to:

- · Be aware of their usual activity pacing patterns
- Understand the impact of reinforcement on their pain and fatigue behaviors

#### **SESSION 3 MATERIALS**

- Session 3 handouts
- Flipchart
- Weekly operant learning group progress chart

#### **SESSION 2 HOMEWORK: FEEDBACK AND DISCUSSION**

- First, have the participants enter their information on the weekly group progress chart.
- When the charting is completed, take about 15-20 minutes to let the group participants discuss their experiences with the following
  - o Did they meet all their weekly goals? If not, what happened?
  - o Did they maintain their routine as scheduled? If not, what happened?
  - o Did they allocate time to their rest periods, and stick to the plan?
  - When using task switching, did they make sure switching was determined by time or quotas that they set?
  - O How did they manage the activity that they avoid the most?
  - o How did they feel when they succeeded at their task?
  - With their general weekly life activities, did they apply some of the pacing techniques? Which ones?
     Did they work?
- Make sure that each participant has a chance to discuss what they were supposed to do during their week. Reinforce their successes and encourage the group to do the same.
- For those who did not meet homework goals in all life domains, ask what happened in an empathic manner so that they don't feel punished. If participants indicate that the pain and the fatigue stopped them, explain the importance of being proactive if they want to achieve their goals (without criticizing them for not completing the task). When participants do not meet a particular goal for 2 weeks in a row, the therapist should ask them to revert to their previous goal and begin increasing again from there. If a participant does not complete their homework due to a lack of motivation, ask them how they are planning to achieve their (specific) goals and what they could do to succeed. Paraphrase adaptive goals and plans. Through this type of questioning and emphatic listening, help them to make a plan that they are confident they can follow.

#### **TEACHING SESSION 3**

# Overactivity, underactivity and "yo-yo" pattern (Handout 15)

- Explain to the participants that when they first started having their pain and/or fatigue, some activities
  became associated with an increase in pain and fatigue. It then lead them to gradually develop expectations
  that these activities would inevitably bring them even more pain and fatigue.
- This learning process in which a relationship between certain activities and pain and fatigue exacerbation has caused gradual changes in their activity pattern to occur over time. This relationship becomes stronger and stronger over a period of months and years, and is accompanied by the development of different pain and fatigue behaviors that are also subject to this conditioning process.
- It is very likely that participants have developed one or more of the following patterns. Describe these
  patterns to the group and discuss the impact on their level of disability, pain, fatigue, mood and quality of
  life.
  - Underactivity: In order to prevent the pain and fatigue exacerbation the individual gradually decreases their activity level over time. By being less and less physically active, the person experiences a deterioration in fitness, which leads to body weakness and muscle stiffness. Increased inactivity results in a further reduction of strength, flexibility and stamina. Inactivity is accompanied by increased disability, more pain and fatigue, poorer mood and lower quality of life.
  - Overactivity: There are also individuals who gradually take on more and more activities despite their pain and fatigue levels, to the point that they can be even more active compared to when they weren't suffering from their chronic pain condition! Sometimes this overactivity is a way of distracting themselves from their pain and sometimes it is a way of "fighting back" ("I'll show that pain!"). Eventually, overactivity can lead to a "crash" where the person is incapacitated and has to take a long recovery time.
  - <u>Yo-Yo pattern:</u> This pattern is a combination of overdoing and underdoing. When the person feels it is a "good day" (meaning that the pain and the fatigue are manageable), they overdo activities in order to get as much done as possible. However, by doing so they exceed their pain and fatigue tolerances which results in an increase in their symptoms and a period of time when they "crash" and are unable to function (e.g., stay in bed). This period of underdoing ("bad days") sometimes lasts for many days. As their symptoms decrease and they start feeling better, they attempt to make up for lost time by again being overactive. This continual up and down pattern is referred to as "yo-yoing".
- All the above strategies are similar in that activities become pain and fatigue contingent rather than quota or time contingent. They cause some false expectations (fear) of pain and fatigue as well as reinforcing maladaptive pain and fatigue behaviors. For example, if they expect to feel pain every time they are gardening, pain will become contingent to gardening. However, if gardening is related to time (watering for 15 minutes) or quota (watering 4 plants at a time) before taking a rest period, the activity of gardening becomes contingent to a certain amount of determined time or quota rather than their pain or fatigue.
- The operant learning approach that we are teaching in this program is designed to help them to get out of this vicious cycle by maintaining moderate activity levels interspersed with limited rest times. This approach will help them to be more active and stop pain and fatigue from controlling their lives. This re-learning

process will decrease their overall disability level and allow them to better balance their lifestyle according to what they have decided they 'want to do' and 'must do'.

#### **EXERCISE**

- Take around 10 minutes to ask the group members to share and discuss their old (unhelpful) activity patterns. Explain that they have to give their opinion about these activity patterns (without getting into a discussion of pain and fatigue).
  - o How do they see themselves? Do they tend to be overdoers, underdoers or both?
  - o How much were they able to accomplish in total with the use of those activity patterns?
  - o Do they still think these patterns are a good way of managing their activities? If yes, ask them to explain their point of view and help them challenge their misconceptions.

#### \* 15-MINUTE BREAK \*

#### **TEACHING SESSION 3**

# The importance of reinforcement, punishment and extinction (Handout 16)

- There are many ways that participants can reinforce themselves for keeping up with their activity-pacing program. Positive reinforcement is an important part which should not be neglected as it will help them (1) to achieve their activity-pacing goals and (2) to reduce pain and fatigue behaviors. It also helps participants to maintain a positive focus and to feel good about the program. For an operant treatment to be helpful, the person must be unhappy with their current activity level.
- Before starting the program many pain and fatigue behaviors might have been reinforced by different consequences and contingencies.
- Everyone's situation is different but, for example, it may be that when they complained about pain, their family took over more of the household chores. When, displaying pain and fatigue behaviors they may have received more attention and support from others, who are concerned about their health. As a result, the person is more likely to use those behaviors. The learning principle is that when a behavior, including pain or fatigue behaviors, is followed by a positive consequence, the probability of this behavior occurring again increases. For example, if they show their appreciation to their spouse when they are taking care of dinner preparation, they increase the probability that their spouse will do it again in the future.
- Avoidance of aversive consequences operates similarly. So, for example, if doing household chores is aversive
  for the person, avoidance of the chore is also reinforcing. For someone who dislikes having to ask for help,
  showing pain and fatigue behaviors is also a way of avoiding direct communication about what they would
  like. There are often multiple learning processes occurring and this pattern leads to the person becoming
  increasingly disabled and adopting the "sick "role.
- Although these patterns are not usually an issue for short-term (acute) illnesses, they develop over time during chronic illnesses and can have a significant negative impact on the individual and their relationships

- with others. As the pattern continues, family members and significant others may become frustrated and switch from being solicitous to withdrawing from or becoming angry with the person. For the person with pain and fatigue, these responses are experienced as punishing.
- A key goal of operant treatment for chronic pain and fatigue is to manage contingencies and consequences so that it is healthier and more positive (i.e., the learning process described above). Contingencies have to be viewed as "if, then" situations that influence what the participant would do or not do. For example: if they moan, then they get exempt from doing the dishes. The probability of this behavior reoccurring is high. The consequence is the result obtained when doing a behavior; here it is avoiding doing the dishes. One way to manage contingencies is to make positive consequences goal or time contingent rather than pain (or fatigue) contingent. For example, if I do the dishes, then I will be able to watch my favorite TV show (consequence).
- A second way to manage these contingencies is to reduce or eliminate punishment and aversive consequences from others. Negative responses from others such as anger, withdrawal, ridicule and removal of pleasurable activities are punishing. The experience of pain and fatigue is also punishing. Operant treatment is most likely to be effective when both these aspects are addressed: increased positive reinforcement of activity and "well" behaviors, and removal of punishers. Here are some common reinforcers:
  - <u>Rest:</u> When participants complete a task (meet a quota or time-based goal) a contingent period of rest
    will positively reinforce their participation in those activities. In contrast, if they rest when they feel
    pain or fatigue they are reinforcing their pain and fatigue behaviors as well as withdrawing from the
    activity.
  - Sense of accomplishment: By having successes in meeting their weekly goals, including their 'almost always avoid' activities, the consequent feeling of accomplishment is positively reinforcing and will motivate them to maintain those healthy behaviors. It may seem like a simple thing but making an entry in their self-monitoring record every time they succeed (by putting a Y = "Yes I did it") will increase their sense of accomplishment.
  - Attention and feedback: Support by their therapist, group participants, and family members, friends
    and co-workers who encourage and support their progress will act as a positive reinforcement for
    pursuit and completion of their goals. The attention and the feedback they receive are not related to
    their pain and their fatigue anymore, but rather reinforce good pacing behaviors (i.e., activity).
  - Rewards: Rewards can take many forms, such as eating sweets, buying something nice, going out, having a romantic night with the spouse, taking a hot bath, watching TV, and so on. Rewards should occur when they have accomplished their weekly goals. For example, if Steve completes all of his weekly pacing homework, he plans to take Sunday afternoon to go to the movies. However, if he doesn't succeed, he will not go and will try to meet his goals next week. Another example is that when Steve completes his morning chores, he then sits and watches an episode of his favorite TV show. If he does not succeed, he will record the show and will watch it when he finishes his chores. It is important for participants to understand how crucial it is NOT to obtain reinforcement until they have achieved their goals. Also explain that they don't have to fit everything in their life into the operant treatment plan. For example, if they enjoy having dinner with their family each evening, they should continue with that routine. It is not realistic to use contingency management techniques for every aspect of their lives. We want to focus on specific pain and disability-related behaviors.

- As noted above, pain and fatigue often act as punishers for activity. For example, going to a pleasurable social event could become aversive if it produces high levels of pain and exhaustion afterwards. Over time, this is likely to lead to the person isolating him or herself more in order to avoid these aversive consequences. By working under their baseline tolerance level and by maintaining a moderate activity level, they can reduce contingent punishment and decrease their level of disability.
- Extinction occurs when the contingent relationship between a behavior and its positive or negative consequence is removed. For example, by ignoring pain and fatigue behaviors the therapist and group members don't reinforce or punish them. This is sometimes most easily done by simply switching the behaviors that are reinforced. So, for example, if the therapist and group members ignore these unhelpful behaviors and reinforces their positive behaviors (e.g., weekly goal attainment), they are both reinforcing adaptive behaviors and extinguishing those that are maladaptive. The same is true with regards to their relationship with others. More details about adequate assertiveness and communication will be addressed in Session 4.

## **SMALL GROUP EXERCISE (Handout 17)**

- In small groups of 2-3 participants, take around 15 minutes to do the following exercise: Ask them to brainstorm to build their own reinforcement handouts. When it is done, ask them to think of ways to implement this in their weekly routine.
- Bring the group back together. Have them share and discuss their ideas. Write different ideas on a flipchart. Ask them how realistic their reinforcement ideas are, to make sure these ideas are applicable.
- For example, a spouse who is not very supportive of their chronic pain condition will be to hard involve as a main source of attention. They might want to involve someone else, like their mother to help them to obtain reinforcement from their program.

#### **HOMEWORK**

#### **ACHIEVING THEIR WEEKLY ACTIVITY GOALS**

- Ask them to use their handout 13 goals for week 3 with their weekly calendar to pre-plan their activity goals.
  - o First, they have to plan when they are going to do each activity on their list. It is important that they adhere as much as possible to their plan in order to maintain their routine.
  - Second, they should maintain their activity even when they feel an increase of pain and fatigue when doing it.
  - Third, they should always take their pre-planned rest periods (but not extend them!) irrespective of pain and fatigue.
- It is important that participants understand that this homework is essential even if they are reluctant to
  work until they feel a pain or fatigue increase. This exercise will allow them to gradually increase their
  activity by pacing using time and quotas, in conjunction with adequate rest time to meet their goals and feel
  less disabled by their chronic pain condition.

# **OPERANT LEARNING SESSION 4**

ADDRESSING PACING CHALLENGES: GROUP SESSION

#### **SESSION 4 OBJECTIVES**

# At the end of this session the participant will be able to:

- Be more assertive (accepting requests from others), and to reduce pain and fatigue behaviors (pain and fatigue complaints and non-verbal behaviors)
- Problem solve when confronted with pacing difficulties, in order to manage activity and rest cycling better.

#### **SESSION 4 MATERIALS**

- Session 4 handouts
- Flipchart
- Weekly operant learning group progress chart

#### **SESSION 3 HOMEWORK: FEEDBACK AND DISCUSSION**

- First, have the participants enter their information on the weekly group progress chart.
- When the charting is complete, take about 15-20 minutes to let the group participants discuss their experiences with the following
  - o Did they meet all their weekly goals? If not, what happened?
  - o Did they maintain their routine as scheduled? If not, what happened?
  - o Did they allocate time for their rest periods, and stick to the plan?
  - When using task switching, did they make sure switching was determined by time or quotas that they set?
  - O How did they manage the activity that they avoid the most?
  - How did they feel when they succeeded at their task? Did they reward themselves? Did they receive
    positive feedback or attention from others? Did they feel a sense of accomplishment? Did they feel
    that the rest period after the task was rewarding?
  - With their general weekly activities, did they overdo, underdo, yo-yo pattern, or use the activity and rest cycling?
  - With their general weekly life activities, did they apply some of the apacing techniques? Which ones?
     Did they work?
- Make sure that all participants discuss what they were supposed to do during their week
- Reinforce their successes and encourage the group to do the same. For those who did not meet homework goals in all life domains, ask what happened in an empathic manner so that they don't feel punished. If participants indicate that the pain and the fatigue stopped them, explain the importance of being proactive if they want to achieve their goals (without criticizing them for not completing the task). When participants do not meet a particular goal for 2 weeks in a row, the therapist should ask them to revert to their previous goal and begin increasing again from there. If a participant does not complete their homework due to a lack of motivation, ask them how they are planning to achieve their (specific) goals and what they could do to

succeed. Paraphrase adaptive ideas and goals to reinforce these. Through this type of questioning and empathic listening, help them to make a plan that they are confident they can follow.

#### **TEACHING SESSION 4**

# Being assertive with others when pacing activities (Handout 18)

- Explain to the participants that they might have previously refused requests from others because of their pain and fatigue levels rather than what they think they 'Must do' or 'Want to do'. Participants will be able to pace better if they can be more assertive when someone is making a request that they do not feel fits with their pacing schedule. It is important to decide whether to accept a request based on their goals rather than their pain or fatigue (or their fear of pain or fatigue). If it fits with their overall pacing plan, it is acceptable for them to agree to requests from others and to meet those requests even though they have chronic pain and fatigue.
- Pain and fatigue should not be the deciding factor if the request is included as a goal. It may be particularly important to fulfill requests that they usually avoid because this will provide them with an opportunity to see what they are actually able to do using pacing rather than having their activities controlled by fear. So, for example, if their spouse would like them to invite another couple for dinner and they have avoided this for months or years, they should give it a try. They should remember that they can use their pacing tools (activity-rest cycling, switching activities, and rewards) to manage that situation and should make a pacing plan in order for the dinner to be successful. In this way they can reclaim aspects of their lifestyle that they may have given up on. More details about managing fear-avoidance will be provided in next week's session.
- Another consideration is that participants who are 'overdoers' or engage in the 'yo-yo' pattern may be at risk of taking on too many requests, particularly if they have difficulty being assertive. It will be important for them to consider their goals and to agree only to requests that fit into their overall activity goals.
- When they decide to accept requests or to help others, they have to pre-plan a way to integrate that task into their activity and rest cycling. Because it is not always possible to assess their baseline tolerance levels before doing the task, they should estimate what will be an acceptable baseline according to their previous pacing experience and to set goals that are 60-75% of that baseline, in order to maximize their chances of success. As with other pacing tasks they should also consider including rest periods and/or task switching when doing these tasks. When it is a task they usually avoid, they might want to ask another person for their support in order to obtain positive reinforcement for accomplishing the task.
- When they agree to requests or decide to help others, they might want to explain their pacing plan to them and let them know how long they expect that it will take them to accomplish the requested task. They should also explain to others that their pacing plan is action focused rather than pain and fatigue focused.

#### Being aware of pain and fatigue behaviors when communicating with others

• Explain to the participants that when their pain and fatigue was in the acute phase there was a need to communicate to those around them what they were experiencing. As their pain persists, however, verbal and non-verbal expressions of pain ("pain behaviors") can begin to negatively affect their relationships with

others. Like all behaviors, pain behaviors are subject to learning processes. So, for example, a person with pain who has difficulty asking for help (feels embarrassed and avoids asking) might learn that when they show their pain to others (e.g., verbal complaints, facial expressions, etc. – see below) others give them help without their having to ask. Whenever the person is in a similar situation they are more likely to show "pain behaviors" because of this learning process.

- It is important to note that, almost always, this learning process is unconscious. That is, the person is not aware that they are learning this response pattern, and they are not intending it to happen. This type of pain and fatigue behavior should be differentiated from "pain and fatigue behaviors" that are an immediate response to a painful stimulus. If you drop something heavy onto your foot, your pain behavior is not learned but rather is a reflexive response to that painful stimulus.
- Nonverbal pain (and fatigue) behaviors can take many forms such as nonverbal utterances (e.g., moans, gasps, grunts, yawns, sighs), body postures, overt behaviors (limping, grimacing, rubbing, guarding, slouching, frowning, lying down, using a heating pad, etc.
- As we have also briefly discussed in Session 1, these behaviors can be reinforced through their environmental consequences over time. Pain and fatigue behaviors will vary from one participant to another, according to the learning processes that have operated within their own environments. For example, displaying pain and fatigue behaviors when starting to vacuum the living room might have signaled their spouse to take over, which increased the probability that these behaviors will recur in that situation in the future. All learned pain and fatigue behaviors are associated with specific antecedents (triggering situations) and reinforcers<sup>4</sup> (e.g. positive consequences). Sometimes participants might even have a discrepancy between their verbal content and the non-verbal behaviors. For example, if they slouch in a chair and don't move (non-verbal behaviors), but at the same time tell their friends that they will be able to walk for an additional 30 minutes (verbal content), others may respond to their behavior (slouching) which will seem more believable rather than their verbal statements (walking). If others encourage the person to continue sitting rather than completing the walk, this response may be a reinforcer and increase the probability that the "slouching" behavior will occur again in the future. In this way the person may, inadvertently, become increasingly disabled. Even if behavior is not reinforced consistently, this learning process occurs. In fact, intermittent reinforcement (that is, reinforcement sometimes but not at other times) is known to entrench learning and make changing behavior more difficult. Learned behaviors have "a life of their own" and are no longer directly associated with pain or fatigue.
- As can be seen from the preceding discussion, the environment is more influential than the participants are
  usually aware of. In order to change these learned behaviors, they now need to become more conscious of
  how others reinforce their verbal or non-verbal behaviors.
- Here are some tips that can be used to help them unlearn these learned behaviors. First of all they should eliminate their learned pain and fatigue behaviors (verbal and nonverbal). Oftentimes, family members, work colleagues or relatives tend to inquire about their pain and fatigue. Questions such as "How is your pain?," "You seem very tired today?", "Did you find new meds to help with your illness?", "Did you ever try using a cane to help you?", and "I can't imagine how you go on with your life" are frequently asked, but are not helpful in helping them to reduce their disability and to increase their quality of life. One way to deal with

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<sup>&</sup>lt;sup>4</sup> A reinforcer is anything that increases the probability that a behavior will be repeated.

such questions is to answer briefly, without putting the focus on pain and fatigue. Simple sentence such as "I am doing fine today, thank you for your concern but I am managing well now" should be used by participants to reduce the attention of others on their pain and fatigue. They should also consider asking those closest to them to ignore their pain behaviors and to provide them with encouragement for completing their goals. In this way, both the participant and the important people in their life are focusing on improvements rather than on pain and illness.

- It is also important that they *accept* positive feedback and attention from others. For example, rather than rejecting support for attaining a goal (e.g., by saying "It isn't that important; anyone could have done it"), they should thank the person and allow themselves to feel good about their accomplishment. If they reject others' attempts to support them, they will be less likely to receive that support in the future!
- Participants need to make sure that their verbal statements match their non-verbal behaviors with regard to pain and fatigue. Being aware of their behaviors is an important key to conveying the right message to others. For example, if they are talking about beginning an exercise but are simultaneously rubbing a painful area and are slouching on the couch, they are sending a "mixed message". The more they are able to be conscious of these unhelpful, learned behaviors, the more they will be able to stop doing them. They should practice observing themselves when they are interacting with others and try to reduce their pain and fatigue behaviors. For example, if they notice they are rubbing a painful area, they could stop doing that behavior right away. With time and practice they will unlearn these behaviors, since they will be no longer be reinforced (extinction principle discussed last week). New more adaptive behaviors will replace the old ones. For example, sitting upright and using proper body mechanics instead of slouching on the couch. There will be further education on proper body mechanics in session 7). These new adaptive behaviors will generally be better for their bodies since they will increase their stamina, strength and flexibility, which will also help to reduce their level of disability.

#### SMALL GROUP EXERCISE – USING ASSERTIVENESS SKILLS (Handout 19)

- Group members are divided into groups of 3 or 4. Each group will participate in one of three role-playing scenarios. Each group will discuss how they would assert themselves in the situations provided. Three scenarios will be written on separate pieces of paper. A person from each group will pick out a scenario.
- Take approximately 10 minutes for the small group discussion. In the groups, participants will be asked to think about whether or not the scenario is a goal, and if so, if it is a 'want to do' or a 'must do'. If the task is a goal (must or want to do), the person must outline their level of participation in this task. The participant is encouraged to use task switching, activity-rest cycling, and rewards when discussing how they would approach the task. If the task is not a goal, the group must present how they would assert what they can or cannot do without talking about pain or fatigue.
- The scenarios that will be written on pieces of paper are as follows:
  - You have a potluck at work and your co-worker wants you to bring the homemade lasagna that you always used to make. What do you say...?
  - You wake up and it is a nice day. Your partner wants you to go to the park for a walk, but you are not feeling up to the usual 30-minute route. What would you say...?

- You have volunteered in the past at work (or community activity coaching, school council, and church function) and you did a great job, but were exhausted by the time you were done. Now... you have identified that you can no longer do it the same way. How would you continue doing this task?
- Once everyone has had a chance to discuss their scenario within their small groups, bring the larger group back together. Ask each subgroup to discuss their scenario and how they were able to use assertiveness skills as well as task switching, activity-rest cycling, and rewards/positive reinforcement. The others will then be asked if they have any further comments or suggestions on how they would have handled the same scenario. Help the group to see that there are many different ways to communicate that are not pain and fatigue contingent.
- Take 5-10 minutes to ask the group participants to talk about other situations during the week where they experienced requests and demands from others that they refused according to their pain and fatigue levels rather than their "Must" or "Want to do"? Ask them how they managed it at the time (e.g. pain and fatigue behaviors) and how they will manage it in the future?

# \* 15-MINUTE BREAK \*

#### **TEACHING SESSION 4**

# **Problem solving when pacing activities (Handout 20)**

- Sometimes, and in some settings (e.g., work), they might find it hard to maintain a stable balance between activity and rest cycling. Since they began these group sessions, they have learned how to use different techniques to help them to better manage their activities. They will learn more techniques and new skills in the remaining sessions.
- However, sometimes they still might fail or be confronted with challenges that they do not know how to
  manage. Can they recall some situations in which their activity/rest cycling did not work out as expected? For
  example, they may have underestimated the amount of time required to cook a special meal for guests and
  overdid activities instead of task switching and taking limited rest periods? They might also have received
  requests from others that they were uncertain how to handle within their activity/rest cycling plan.
- Problem solving will help them to better assess these types of situations in order to maintain their pacing goals.
- **Specifying pacing problems:** Sometimes, participants might not be able to clearly identify the pacing problems that they are having. So it is important to clarify the situation first by putting it into context.
- Example:
  - Julie wants to volunteer to supervise playground activities at her children's school. However, in order to do this work she is expected to commit 2 hours, 2 times a week and will not be able to take breaks while she is supervising the children. This example provides a clear description of a situation that is now solvable.
- What are the barriers to maintaining their pacing strategies? This aspect of pacing is likely something that they are (unconsciously) doing as part of their weekly goals schedule. If they are confronted with an unexpected event, they should step back from the situation before proceeding. This pause will allow them to

take a few minutes so that they can problem-solve adequately and allow them to make better decisions. This is likely to enable better activity and rest cycling.

# Example:

- Julie knows that she has a hard time standing for prolonged periods of time. Her baseline tolerance is around 30 minutes.
- She finds it mentally demanding to watch six children simultaneously. She is usually able to maintain her attention span with kids for around one hour.
- She is not sure how she will be able to bring the play material from the storage room to the playground. Julie knows that if she carries these materials alone, she will exceed her pain and fatigue tolerance. She also usually avoids carrying heavier things.
- What are alternative pacing solutions that are available? Defining the exact challenges involved in situations will help participants to generate solutions and think about the available options. They should be encouraged not to censor themselves because they think their ideas are 'stupid' or 'silly'. They should try to be as creative as they can; even the most outlandish possibilities are worth considering, as they might lead to novel solutions. This is also a good time for them to think about applying the techniques that they have learned in their previous sessions.

#### • Example:

- o In Julie's case she could sit down every 20 minutes (work at around 80% of baseline tolerance) to take a 5 minute rest period and alternate like this for a period of two hours. She could lean on a tree or a wall on a building every 20 minutes to take a 5 minutes rest periods. Every 45 minutes she could request help from the other volunteers in the playground so that she could take 10 minutes to relax. She could also plan a calm activity for the children (eating a snack or listening to a story) every 45 minutes.
- Rather than carrying the materials all at once, Julie could decide to carry them using a quota of 4 objects at a time, and alternating carrying the objects with 2 minutes of rest. She could also ask the volunteers in the playground to help her, but still carry what she can (4 items). She could then gradually increase the amount that she carries every week. Alternatively, she might decide to carry everything at once, but take many small rests in order to get everything to the playground.
- Look at the pros and the cons of every activity pacing solution: They first need to weigh every solution by examining the pros and the cons in order to come up with an effective but realistic solution. They should also consider combining solutions.

# • Example:

- o For the problem of prolonged standing in Julie's case: If she sits on the ground she will rest and be able to still watch the children but this will be better than lying down. Leaning on the tree will be somewhat helpful but not as helpful as resting and then sitting or lying down for a limited period of time.
- For the mentally demanding task: she could ask another volunteer to help every 45 minutes, but they
  might not agree to this as they need to take care of their own groups of children. If she plans two 15
  minutes breaks at 45 minute intervals during which the children are read a story or given a snack to
  eat, she feels that the children will lose some play time because of her.

- o For the playground materials: if she carries 4 items at a times, she will have to do 3 trips to the playground and the materials could be stolen in the meantime; if she asks a volunteer to help with the materials and she carries 4 items she will get everything to the playground and will be able to spend some time socializing with the other volunteers, if she does many small stops, the children will become impatient because they have to wait too long to reach the park.
- <u>Finalize their pacing solutions</u>: They should choose the solutions that will allow them to pace themselves as well as they can, so that they can reduce their level of disability. Remember, a solution can sometimes be to use task switching rather than taking a rest. It is important to find creative ways to reduce avoidance of tasks that they have identified as 'Must do' or 'Want to do'. It is also important to find an effective way to take limited rest times since their activity levels should be within their baseline pain and fatigue tolerances, while also allowing them to achieve their goals.

#### Example:

- Volunteering at school is an activity that Julie has wanted to do for the past year, but has avoided because she wasn't sure she could handle the demands that are involved. She decides to sit for 5 minutes at 20 minutes intervals (to rest properly) while continuing to watch the children in the schoolyard. She plans to slowly increase her standing time up to 45 minutes over the next 3 months. She will plan two 15 minutes breaks for the children after they have had 45 minutes of play time, during which she will reward their quiet behavior with a small snack and an interesting adventure story that they look forward to hearing each time she volunteers. She also decides to ask a volunteer to help her to carry the materials. However, she makes sure to minimize her pain and fatigue behaviors, and to carry 4 items instead of avoiding the task. She thinks that over the next three months, she can work up to carrying 8 items by slowly increasing the total amount of weight.
- Evaluation of the impact of the pacing plan: After they have made their plan, they will then have to try it out in order to see how well it works. Some adjustments will likely be needed along the way. If they find their solution was not optimal, they can always go back to their solutions list and try something else. It could also happen that other options become available to them as they carry out their plans. They should readjust their plans so that they provide the greatest functionality.

#### Example:

o After implementation, Julie realized that she had overestimated her standing time, so she decided to also switch tasks every 10 minutes to lean on the tree. By standing 10 minutes, leaning 2 min, standing 10 min and sitting 5 minutes she was able to maintain the activity (volunteering) for 2 hours and is now slowly starting to increase her standing time. She had developed a nice relationship with another volunteer and rarely shows any pain or fatigue behaviors. She is now able to carry more items to the playground and she receives positive feedback and encouragement from the other volunteer. The children seem very enthusiastic about the snacks and stories, and Julie also finds this time very relaxing. Julie also has more things to talk about during family dinners on the nights she volunteers, which is also rewarding for her. Her sense of accomplishment provides motivation to continue the task that she set out to do.

#### SMALL GROUP EXERCISE - PROBLEM SOLVING

- In small groups of 3-4 participants, take approximately 10-15 min to do this exercise. Have the participants use the problem solving and assertiveness handouts (18 and 20) to manage the following situation: Your friend asks you to help her organize a special dinner with 8 invited guests. She tells you she knows how talented you are at doing these types of events (which is actually true). She would like you to plan the entertainment for the night, choose the menu with her, cook the meal with her and help her clean up after the guests leave. What do you say to her?
- Bring the group back together and ask them to choose one participant from every subgroup to share their ideas. How did they arrive at their solution? Did they include pre-planned rest periods?
- Help the group understand that there are many different ways to deal with an pacing problem. There is no single "right" solution.

#### **HOMEWORK**

#### **ACHIEVING THEIR WEEKLY ACTIVITY GOALS**

- Ask them to use their handout 13 goals for week 4, along with their weekly calendar to pre-plan their activity goals.
- First, they have to plan when they are going to do each activity on their list. It is important that they adhere as much as possible to their plan in order to maintain their routine.
- Second, they should maintain their activity even if they feel a slight increase of pain and fatigue when doing
   it
- Third, they should stick to their planned rest periods without extending them, even if they feel pain and fatigue.
- It is important that participants understand that this homework is essential even if they are reluctant to work until they feel a pain or fatigue increase. This exercise will allow them to increase gradually their activity levels by pacing (using time limits and quotas as well as adequate rest time) to meet their goals so that they feel less disabled by their chronic pain condition.

# **OPERANT LEARNING SESSION 5**

PAIN AND FATIGUE AVOIDANCE: GROUP SESSION

#### **SESSION 5 OBJECTIVES**

# At the end of this session the participant will be able to:

- Be aware of social responsiveness of others when interacting
- Understand how to counter pain and fatigue avoidance
- Understand and apply shaping and the Premack principle

### **SESSION 5 MATERIALS**

- Session 5 handouts
- Flipchart
- Weekly operant learning group progress chart

#### **SESSION 4 HOMEWORK: FEEDBACK AND DISCUSSION**

- First, have the participants enter their information on the weekly group progress chart.
- When the charting is completed, take about 15-20 minutes to let the group participants discuss their experiences with the following
  - o Did they meet all their weekly goals? If not, what happened?
  - Did they maintain their routine as scheduled? If not, what happened?
  - o Did they allocate time for their rest periods, and stick to the plan?
  - When using task switching, did they make sure switching was determined by time or quotas that they set?
  - O How did they manage the activity that they avoid the most?
  - How did they feel when they succeeded at their task? Did they reward themselves? Did they receive positive feedback or attention from others? Did they feel a sense of accomplishment? Did they feel that the rest period after the task was rewarding?
  - o For their general weekly life activities, did they use assertiveness skills by accepting demands or by providing assistance to someone? How did they manage the task? If they say no, ask them why? Were some activities pain or fatigue contingent?
  - Where they more conscious of their verbal and non-verbal pain and fatigue behaviors when they were interacting with others? What did they observe? Did they try to stop their habitual pain/fatigue behaviors? What happened?
  - With their general weekly life activities, did they apply some of the pacing techniques? Which ones? Did they work?
- Make sure that all participants discuss what they were supposed to do during their week
- Reinforce their successes and encourage the group to do the same.
- For those who did not meet homework goals in all life domains, ask what happened in an empathic manner so that they don't feel punished. If participants indicate that the pain and the fatigue stopped them, explain

the importance of being proactive if they want to achieve their goals (without criticizing them for not completing the task). When participants do not meet a particular goal for 2 weeks in a row, the therapist should ask them to revert to their previous goals and begin increasing again from there. If a participant does not complete their homework due to a lack of motivation, ask them how they are planning to achieve their (specific) goals and what they could do to succeed. Paraphrase adaptive goals and plans. Through this type of questioning and emphatic listening, help them to make a plan that they are confident they can follow.

# **TEACHING SESSION 5**

# **Overcoming social isolation (Handout 21)**

- In Session 4, we discussed in detail their ways of communicating their pain and fatigue verbally and non-verbally with others in their environment (i.e., spouse, family, friends, colleagues etc.). We have also talked about how others are positively or negatively reinforcing certain pain and fatigue behaviors within their environment. Finally, we discussed new ways that they could behave that are not pain or fatigue contingent but are related to what they think they 'Must do' or 'Want to do'. We would now like to further explore how their chronic pain and fatigue condition has changed their relationships with others.
- Some participants might have found that as their pain and fatigue persisted for months or years, they have gradually become more socially isolated. As a result of their pain or fatigue, they might have become less interested in socializing with others. Unfortunately, some participants may have lost relationships because of their pain and fatigue condition. More subtle forms of social isolation may have also occurred, in which they feel that although people remain involved in their lives; their attitude toward them has changed.
- When their pain and fatigue first started they might have noticed that others showed positive responses toward them, including attention, support, and reduction of expectations, taking on more responsibilities, providing assistance, and being more understanding and caring. However, as the condition became more chronic, participants might also have noticed that others began to show more negative responses and may have developed a tendency to: give unsollicited advice (e.g., "you should get back to work", "you should try a sleep medication", "you should put magnets in your mattress"), focus more on their pain and fatigue and view them more as a 'sick' person (e.g., "How is your pain, you seem exhausted today? Did you talk about your physician to get into physiotherapy yet?") instead of seeing them as a whole person, including their positive qualities and interests. They might see them as 'invalid' and insist on taking over some of their responsibilities (e.g., "I will come on Thursday to help you to with your child and do some housecleaning"). This might cause the participant to become more and more disabled, inactive and discouraged. Yet others in their lives might become increasingly frustrated and angry about their limitations (e.g., "It isn't fair that I have to do all the chores alone", "You don't seem to be able to do anything anymore!"). As this frustration increases and persists, significant people in their lives might start ignoring, avoiding or withdrawing from them as they learn that they can't 'cure' their pain and fatigue and that little of what they do makes a difference. It is normal for other people to withdraw when they feel frustration, guilt, disappointment, helplessness, etc. Their lives have changed too and the person with the chronic illness is 'not the person they used to know'. In operant learning terms, some of these responses from others will act as "punishers" that will result in lower activity levels. Other responses (e.g., taking over responsibilities without the participant having to ask) can positively reinforce inactivity and disability (see Session 3).

- To overcome social isolation, participants should use their new pacing skills (activity-rest cycling, task switching, staying within quota or time limits, rewards, communication, and assertiveness skills); more particularly those learned in Session 4, so that they focus less on their pain and fatigue and reduce their "sick role" during their interactions with others.
- They should become more consciously aware of the reactions of others toward them to use the operant learning principles to their advantage and to increase the quality of their social relationships.
- For example: Michael used to have lunch every Thursday with his friend John. Since Michael has had chronic pain and fatigue, their conversations at lunch became more focused on Michael's pain, fatigue, frustration, limitations, etc. As their communication changed in this way, there was little opportunity for John to talk about his life and about the interests that he and Michael have in common. Eventually, John began to meet Michael for lunch less often, to the point where they barely see each other at all. When he realized what was happening, Michael decided that the next time he met John for lunch, he would not talk about his health problems at all. If John asked, he would just say that he was doing fine and that he would prefer to talk about something more interesting. In addition, he decided that he would show fewer habitual pain behaviors (e.g., moaning and rubbing painful areas) as he knew that doing this always "hijacked" their conversation away from more positive topics. Michael was determined to follow this plan so that he wouldn't lose his relationship with John and implemented his plan at their next lunch. After the lunch, John stated that he had enjoyed their time together and that Michael seemed more like his "old self". They both decided that they should resume their weekly lunches.
- Another example: Mary became more active doing housework since she started her activity pacing program. However, it was difficult for her husband to get used to her doing more because he was afraid that it might harm her. He was vigilantly monitoring her behavior for signs of overactivity (pain and fatigue behaviors) and as soon as he noticed something, he would insist that she go lie down and he would take over her chores. Mary was frustrated that her husband was taking over her responsibilities and felt that he was treating her as if she was incompetent. She discussed her feelings with him and asked him to allow her to do her household chores without intervening. She reassured him that she would use her pacing skills so that she wouldn't "overdo" activities. Mary also requested that he help with her 'need to do' tasks by encouraging her and thanking her (positive reinforcement) when she completed her weekly goals. Within a few weeks her husband started worrying less about her condition and was happy that she was doing more in the house and meeting her goals. They decided together to reward her achievements by going out to a restaurant every week that she met her goals. Not only were Mary and her husband happy about her improvements but they also noticed that their relationship had become closer and more positive.
- Participants should take some time to plan for how they are going to manage their pain behaviors, their cues, and their consequences. They should start with one situation (e.g., Michael's lunch with John). If the situation requires a gradual increase in activity level, they should go slow (i.e. under their actual capacity) and gradually increase that activity. They will observe that others will slowly learn that the participant is less disabled and less focused on pain and fatigue. With time, relationships will normalize and revolve less around the pain and the fatigue.
- Overcoming social isolation and including others to help them maintain their weekly goals will have a
  positive impact on their mood, quality of life, etc. Social feedback and attention can be a powerful positive
  reinforcer to help them maintain their treatment gains over time.

#### SMALL GROUP ACTIVITY - PAIN AND FATIGUE BEHAVIORS

- This small group activity will start to get group members to identify their pain or fatigue behaviors and what
  the consequences of these behaviors may be. Ask participants to write down on a piece of paper what they
  think is a pain behavior that they do, fold it up and put it into a bowl.
- All behaviors will then be pulled out of the bowl (without knowing who wrote each one). The participants
  would then discuss the different behaviors and the consequences that they think these particular behaviors
  would bring.
- Ask: What does this pain behavior tell you? How would you react to this type of behavior?
- This activity will allow the group members to see how important their nonverbal behaviors affect communication with other people.

#### \* 15-MINUTE BREAK \*

#### **TEACHING SESSION 5**

# Pain and fatigue avoidance (Handout 22)

- Explain to the participants that there is a learned behavior pattern called escape-avoidance that is common in people with chronic pain. After a while, they become fearful of engaging in activities in case those activities result in an increase in their symptoms. This fear of pain (or fatigue or further injury) causes them to avoid activity and, consequently, increases their level of disability. In many instances, the fear of pain and fatigue can be more disabling than the pain or the fatigue itself. This behavior persists because it is reinforced by the reduction in anxiety when the activity is avoided. Because the person never has the opportunity to learn that they can do an activity without significantly increased pain, fatigue or harm, the avoidance behavior persists rather than being unlearned ("extinguished"). For example, a person who is fearful that exercise might increase their pain significantly may avoid exercise, preventing themself from having the opportunity to learn that they are capable of exercise.
- For this reason, activity pacing program participants have been asked to pick a task that they are avoiding in their 5 life domains as part of their weekly homework. A plan is made that will allow them to confront their escape-avoidance patterns in order to get a clearer idea of their physical capacity. It should be noted that almost everyone feels a bit apprehensive about doing an activity that they have been avoiding for a long time. They should be encouraged to trust the process, since it has been successfully applied throughout the world. This doesn't mean that they will never have any increase in pain or fatigue (they already do at times!) and they should understand that some increase in muscle pain is normal and healthy for people who are increasing their amount of exercise. They should work on their avoidance-escape behaviors not only when they are doing their weekly homework goals but also when integrating these new skills into their lifestyle.
- An important point is to remind participants that all behaviors that have been learned through operant
  conditioning processes can also be unlearned. This teaching session will give them tools to help them to
  overcome pain and fatigue contingent behaviors that are preventing them from living fuller and more
  satisfying lives. When working on being able to do activities that they have avoided the most, it is important

- that they stay positive by making sure that they reinforce themselves accordingly by using rewards, attention and feedback from others, a sense of accomplishment and taking planned rest times.
- Completing planned tasks: Participants should prepare themselves by scheduling activities that they avoid (but would normally wish to do) so that they provide themselves with opportunities to learn that anticipated aversive consequences (e.g., severe debilitating pain) do not occur. It is especially important for the participants to complete their activity without engaging in escape-avoidance behaviors. Escape from or avoidance of an activity that they fear will make their fear and anxiety related to that activity worse. They should stick to their plan even when they feel apprehensive. To maximize their likelihood of success, they should set their goal low and increase them slowly. That is, they should set a baseline activity level that is about 60% of their tolerance level (i.e., 60% of what they are able to do or, if they are unsure, 60% of what they anticipate they will be able to do). For example, if their feared activity is riding a bicycle and they think that they can ride for 15 minutes, they should start at 9 minutes. It is always better to begin with a goal that is less than their actual capacity, and to pre-plan a rest time a little bit under what they expect it would take them to recuperate from the activity (e.g., 15 minutes).
- Being aware of discriminative stimuli: Especially with escape-avoidance behaviors, discriminative stimuli should be considered. Discriminative stimuli, also called "antecedents", are stimuli (situations, people, physical sensations, time of day, etc.) that act as cues that indicate to the person that a particular behavior (e.g., lying down, taking medication, rubbing painful areal, limping, asking for help, guarding etc.) is likely to result in a particular consequence. Pain and fatigue behaviors often come under the control of these discriminative stimuli so that the behavior continues to occur even when no consequences for the avoidant-escape behavior occur. Participants can learn to identify their own discriminative stimuli and choose to alter their behavior in such situations. For example, a little bit of pain from a movement could act as a discriminative stimulus to lie down and rest for 30 minutes with a heating pad and avoid the activity that they had begun. Pacing techniques can be used to prevent this response so that the person continues the activity and meets their goal. The person will then maintain the movement for a certain amount of time (e.g. 5 min) or a quota (e.g. 3 times) and will then take a limited rest (e.g. 20 min).
- Being aware of safety behaviors: Safety or protective behaviors are usually an important part of learned escape-avoidance activity. Like discriminative stimuli (i.e., environment cues) they are maintaining the participants' fear of engaging in activities they are actively avoiding. Safety behaviors can take many forms and they are generally more pain than fatigue related. Safety or protective behaviors can include such things as guarding, holding, bracing, seeking physical support, etc. For example, when Lisa is going grocery shopping she makes sure that she goes on a day when the store is not too crowded. She also looks at other people's carts because she is worried about getting bumped by someone else. When someone is too close to her she holds her arm and braces herself to prevent injury. Lisa was not previously conscious of these safety behaviors but she chooses to do her grocery shopping during "off" hours, she is vigilant of other shoppers and she constantly protects painful parts by bracing herself when someone gets too close. Now that she is aware of her safety behaviors, Lisa decided to set weekly goals, including doing her grocery shopping during more crowed store hours, consciously stopping her 'guarding' behaviors and focusing less on other shoppers by thinking more about the groceries she needs to buy. In doing this, after only a few shopping trips she has become less fearful of grocery shopping at stopped avoiding it.

#### SMALL GROUP ACTIVITY – DISCRIMINATIVE STIMULI AND SAFETY BEHAVIORS (Handout 23)

- Take 5-10 minutes to write down, on Handout 23, what they use as discriminative stimuli and safety behaviors during activities that they usually avoid.
- After they have written down a few examples, ask participants to get with a partner and discuss both the discriminative stimuli and safety behavior and why they use them?
- Is it a good strategy for managing their activities? What is the outcome of using these strategies? Is there a better way to manage the situations?

# Pain and fatigue avoidance, cont'd (Handout 22)

- <u>Shaping:</u> If a participant is avoiding a task to the point that they feel unable to even try it, they can use a strategy called shaping to help them. Shaping involves reinforcing behaviors that help the person move closer to doing a "target" behavior. Shaping involves providing reinforcement for behaviors that get closer and closer to that target (successive approximation) and continue until the target is reached.
- Example: Margaret avoids going out during the winter because she is afraid that she will slip on a patch of ice and hurt herself even when conditions aren't icy. When it is absolutely necessary to go out, she uses a cane. At first, Margaret was too fearful to even go out for 2 minutes without her cane. Shaping was used (only when walking conditions were safe!) to help her reach the target of walking for 20 minutes without a cane. At first, she used the cane for the entire 20 minutes. Next, she used the cane for 18 minutes and carried it for 2 minutes. The amount of time she carried the cane was increased in additional 2-minutes steps until she carried her cane for the entire 20 minutes. Finally, she went out without taking the cane. Margaret reinforced herself by having a hot tea and cookies each time she went out. By the end of this time period, Margaret was no longer fearful of leaving the house without her cane and she was able to go visit her sister who lives 3 blocks away. Margaret no longer uses tea and cookies to reinforce herself because the natural reinforcers of visiting her sister and her satisfaction with being able to leave the house have replaced them. Using the cane had been causing pain in her contralateral hip and now that is also getting better. In this way, she replaced a fear-related behavior with a goal that she wanted to achieve (visiting her sister).
- The Premack Principle: Participants can use the activity that they avoid the least to reinforce the one that they avoid the most, to help them modify their pain and fatigue behaviors. This principle states that they should do activities that are less desirable or avoided before more desirable activities. This more desirable activity will serve as a positive reinforcer for doing the avoided activity. For example, if they avoid exercise they should do this first thing in the morning and follow it with an activity that is more rewarding to them. Selection of rewarding activities is very personal: what is rewarding for one person might be avoided by another! So it is important that participants choose reinforcing activities that they find rewarding, not based on a general rule or what others think is rewarding.

#### SMALL GROUP ACTIVITY – SHAPING AND PREMACK PRINCIPLE (Handout 24)

- This exercise involves the participants thinking of how they would apply Shaping and the Premack Principle.
   The large group is divided into two subgroups. Each subgroup is asked to come up with two different activities that they usually avoid.
- The groups are asked how they would apply both Shaping and the Premack Principle to the activities. Participants are to use handout 24 to write down the activities as well as their plan using shaping and the Premack principle for their chosen activities.
- The subgroups reconvene and are then asked to share both their activities and how they would apply shaping and the Premack principle to the activities. This exercise will help to show them how they can do activities in different ways with applying different pacing principles.

#### **HOMEWORK**

#### **ACHIEVING THEIR WEEKLY ACTIVITY GOALS**

- Ask them to use the handout 13 goals for week 5 with their weekly calendar to pre-plan their activity goals.
- First, they have to plan when they are going to do each activity on their list. It is important that they adhere as much as possible to their plan in order to maintain their routine.
- Second, they should maintain their activity even when they feel an increase in pain or fatigue when doing it.
- Third, they should always take their pre-planned rest periods (but not extend them!) irrespective of pain and fatigue.
- It is important that participants understand that this homework is essential, even if they are reluctant to work until they feel a pain or fatigue increase. This exercise will allow them to gradually increase their activity by pacing using time and quotas as well as adequate rest time, in order to meet their goals and feel less disabled by their chronic pain condition.

# **OPERANT LEARNING SESSION 6**

**REASSESSING ACTIVITIES: GROUP SESSION** 

#### **SESSION 6 OBJECTIVES**

# At the end of this session the participant will be able to:

- Be aware of their pain and fatigue behaviors and how to modify them
- Understand the concepts of intermittent reinforcement and modeling
- Reassess their activity pacing weekly goals and adjust them appropriately

#### **SESSION 6 MATERIALS**

- Session 6 handouts
- Flipchart
- Weekly operant learning group progress chart

#### SESSION 5 HOMEWORK: FEEDBACK AND DISCUSSION

- First, have the participants enter their information on the weekly group progress chart.
- When the charting is completed, take about 15-20 minutes to let the group participants discuss their experiences with the following:
  - o Did they meet all of their weekly goals? If not, what happened?
  - o Did they maintain their routine as scheduled? If not, what happened?
  - o Did they allocate time for their rest periods, and stick to the plan?
  - When using task switching did they make sure it was determined by time or quotas that they set?
  - How did they manage the activity that they avoid the most? Did they use session 5 strategies (Premack, shaping, cues, safety behaviors, completing the task)
  - How did they feel when they succeeded at their tasks? Did they reward themselves? Did they receive
    positive feedback or attention from others? Did they feel a sense of accomplishment? Did they feel
    that taking a rest period after the task was rewarding?
  - O Did they change their interaction patterns with others during the week? Did they observe any changes in their relationships with others (such as getting more positive comments from them)? Were they aware of their pain and fatigue behaviors? How did they manage their pain and fatigue behaviors during their social interactions (i.e. not showing them)?
  - O During the week, did they try some activities that they usually avoid? Which ones? Were they able to complete their planned goals? Where they aware of environmental cues and their safety behaviors? Did they use shaping or the Premack principle to help them overcome their activity avoidance? Did they get rewarded by others or themselves afterwards?
  - Overall, in the last week, did they apply some of the activity pacing concepts? Which ones? Did it work?
- Make sure that all participants discuss everything they were supposed to do during their week
- Reinforce their successes and encourage the group to do the same.

• For those who did not meet their homework goals in all life domains, ask what happened in an empathic manner (so that they don't feel punished). If participants indicate that the pain and the fatigue stopped them from completing their goals, explain the importance of being proactive if they want to achieve their goals (without punishing them for not completing the task). When participants do not meet their goal for 2 weeks in a row, the therapist should ask them to return to their previous goal and, from there, begin increasing again. If a participant does not complete their homework due to a lack of motivation, ask them how they are planning to achieve their (specific) goals and what they could do to address any barriers. Paraphrase adaptive goals and plans. Through this type of questioning and emphatic listening, help them to make a plan that they are confident they can follow.

#### **TEACHING SESSION 6**

# Pain and fatigue behavior management (Handout 25)

- It has now been almost one and a half months that participants have been managing their activities using their new pacing skills. Participants might start to recognize that some of their previous pain and fatigue behaviors have changed over time because they have not been reinforced. That is, they might have experienced extinction or a reduction in the frequency of certain pain and fatigue behaviors, which in return, increased their overall functionality, mood and quality of life. Remind participants that these changes have occurred as a result of them (a) becoming more aware of and changing their pain and fatigue behaviors and (b) changing their consequences (e.g., reinforcers) so that they have a new set of more helpful behaviors.
- Over the last 5 sessions, participants have modified their behaviors by using activity and rest cycling, working at 60% of their pain and fatigue tolerance levels, positively reinforcing themselves with rest, obtaining feedback and support from others, having a sense of accomplishment, and rewarding themselves when they achieve their weekly goals. A key point is that with these new ways of pacing their activities are no longer contingent on their pain and fatigue. They are able to accomplish important life goals. This conditioning process increases the probability that they will respond adaptively when they are confronted with different kinds of life tasks, even those that they avoid the most.
- Participants have also learned to modify their ways of interacting with others by reducing and stopping their (verbal and non-verbal) pain and fatigue behaviors. At the same time, they have increased the quality of their communication with significant others. The changes that they have made in their behaviors might also have improved their overall relationships with others so that these are more rewarding and they feel less socially isolated. They have also regained their previous social roles so that they are more involved, and have also regained some of their "normal" responsibilities, which is rewarding for them.
- Participants have been challenging themselves every week with activities in different life domains that they usually escaped/avoided for fear of pain and fatigue. They have decreased or stopped their safety behaviors and are more aware of environment cues. They have also completed their planned goals and used shaping when the task was initially too difficult for them. They used Premack's principle (i.e. doing an avoided activity before one that is more pleasurable) to reinforce strategies that expose them to the activities that they avoid most. By doing so they have learned that they can do more without significant increases in pain or fatigue and without reinjuring themselves.

- Behavior modification using modeling techniques: Being with the other group members who are successfully increasing their activity levels can also exert a positive influence via "modeling". Modeling is a concept from Social Learning Theory that involves learning by example. When participants observe others progressing and doing more activities, particularly those that they have avoided, it is more likely that they will attempt similar behavioral changes. More broadly, participants may also be able to think of individuals in their lives who exemplify successful pacers.
- <u>Generalization</u>: Generalization can be described as the expansion of the participants' -pacing skills beyond the context of their weekly homework exercises. Generalization implies that the participants are able to apply and adapt their learned pacing strategies to other areas of their lives. Generalization also involves naturally occurring reinforcers taking over from those that have been 'planned'. For example, if participants are now able to do an activity that they enjoy, the pleasure that they get from simply doing the activity will maintain it.
- Intermittent Reinforcement: Finally, as time goes on, and as part of generalization, positive reinforcement is not necessary each and every time that they accomplish a task. It can be expected that reinforcement will become intermittent. It is important to know that this is a normal part of the operant learning process and that it will actually strengthen the new pattern of activity and make it more durable. For example, it is very unlikely that they will be reinforced with a "thank you" by their spouse every time that they empty the dishwasher. An intermittent "thank you" will be enough to encourage them to continue the task. Also, keeping a general sense of their accomplishments each day (rather than for completion of all individual tasks), they will receive sufficient reinforcement to maintain their weekly goals schedule. They should also plan for the program becoming bi-weekly at the end of this month which means that the encouragement and support they receive from the therapist and other group members will gradually become more intermittent. During this period of generalization, it is also important for them to include a limited amount of rest time so that they don't fall into "overdoing" or "yoyo" patterns of activity rather than a stable activity/rest cycle. However, it is essential that rest is not pain or fatigue contingent. Some activities may now only require intermittent reinforcing.

# **EXERCISE – GROUP DISCUSSION ON PAIN AND FATIGUE BEHAVIOR MODIFICATIONS**

- Take around 10-15 minutes to discuss and share the following with participants
  - Have they noticed any change in their behaviors since they have started their pacing program? Which ones?
  - O Did they observe any changes in how rewarded they feel (the reinforcements that they are given)?
    Which ones?
  - Ask them to provide some examples of pacing challenges that they have experienced when they were trying to change their behaviors so that they were more helpful? What happened? Which strategies did they use to manage? (e.g. communication, problem solving, stopping pain and fatigue behaviors etc.)
  - o Have they found their life more rewarding since they started the pacing program? How?
- Make sure to reinforce and encourage participants according to the behavior changes they have made through their pacing program.

#### \* 15-MINUTE BREAK \*

#### **TEACHING SESSION 6**

# **Reassessing activities**

- As participants review the progress they have made over the past 5 weeks, they may have already started
  reassessing what they are actually able to do. Some participants may have discovered that they were able to
  do much more than what they had expected, and others might feel less disabled by decreasing excessive
  activity levels that were followed by prolonged rest ("yo-yoing"). A more balanced approach to activity
  results in an overall increase in activity level.
- By pacing and managing their life activities better, participants may have learned more about themselves, including what they think they 'must do' and what they 'want to do', their baseline tolerance level, that previously avoided activities are now achievable, that they now choose to associate more with people who reinforce their higher activity level rather that with those who reinforce disability, etc.
- These changes can lead to a shift in their life activities such that they are chosen on the basis of their interests and needs, rather than being controlled by pain and fatigue.

# **INDVIDUAL EXERCISE – BUILDING WEEKLY GOALS SHEET (Handout 26)**

- Explain to the participants that they will have to build a new plan to meet their weekly goals for weeks 6 to 12. They can decide to use their previous weekly goals and continue to increase their activity slowly by using task switching and limited rest periods.
- For example, if they are now bicycling for 15 minutes and take a 5 minute break after completing the task, they might want to prolong this exercise using activity and rest cycling. On the other hand, they might have other activity goals that they would like to accomplish instead. They might feel that their current goals are less of a priority or that it was easier to do a previously avoided activity than they expected. If this is the case, they may choose to replace those activities with new ones. For example, if they realize that going to the movie theater with friends is easy and that there is no point in continuing to increase this activity (they no longer avoid it and it is well integrated into their lifestyle), they may want to try to work on a more challenging activity. They may even be able to use previously avoided activities (e.g., going to a movie) as a reward for completing additional activities! Remind them that the most important point is that their weekly goals should be easily achievable.
- They need to remember to work at 60% of their estimated pain and fatigue tolerance baseline level. Part of
  making activity achievable is to think about how realistic it is to accomplish each goal in the context of the
  whole activity list on their weekly schedule. For example, they might want to start slowly by only focusing on
  three weekly chores. This limit might seem reasonable if they are working.
- Their plan must be made using the following rules:

- o Minimum of 1 avoided (between 0 and 3 on the avoidance scale) activity per area of their life.
- Minimum of 1 'Want to do' activity per life area.
- Allow them a period of 15-20 min to complete their goal plan. Check on them individually to make sure they
  are building a realistic plan and to help them if needed.<sup>5</sup>
- Bring the group back together and ask each member to share what they intend to include in their goals for weeks 6 to 10. Reinforce and encourage the group for completing their weeks 1 to 5 goals. If you find that a participant sets their goals unrealistically high (or too low), help them select a lower (higher) starting goal.

# **TEACHING SESSION THREE (Handout 27)**

- Devices can be used to help maintain their quotas and achieve their goals. The use of devices will help
  participants stay within their baseline level of activities and then eventually increase their participation in
  their daily activities. Appropriate use of these devices will help minimize the underdoing, overdoing, and yoyo patterns of behavior. Using these strategies, participants will have a more balanced approach to activity
  resulting in an overall increase in activity level<sup>6</sup>.
- During this session, various devices (timers, pedometers, heart rate monitors, and odometers) will be demonstrated to show how they can be incorporated into daily activities.
- A **timer** is a device used for measuring and signalling the end of time intervals (timer on stove, egg timer, watch, phone),
- A **pedometer** is a device, usually portable and electronic or electromechanical, that counts each step a person takes by detecting the motion of the person's hips.
- A **heart rate monitor** is a personal monitoring device that allows a subject to measure or record their heart rate in real time,.
- An odometer is an instrument that indicates distance traveled by a vehicle or bicycle.
- Approximately 5 minutes will be used to demonstrate the above devices. The group will be given 10 minutes
  to try out the above devices so that they can see how they would help them achieve or increase their
  participation in a particular task.

# GROUP EXERCISE – INCORPORATING PRINCIPLES OF OPERANT LEARNING WITH HEALTH PROMOTING DEVICES (using Laundry as the activity)

- Ask participants how the task of doing laundry can be adapted using some of the principles the participants
  have learned to date (Baseline setting; Pre-planning; Activity and rest cycling; Breaking tasks into pieces;
  Rest and task switching; Positive reinforcement; Punishment; Extinction; Assertiveness and Communication;
  Problem-solving; Escape-avoidance; Completing avoided tasks; Discriminative stimuli; Safety behaviors;
  Premack Principle; Shaping; Modeling; Planning short, medium and long-term goals; Speeding up;
  Normalizing activity levels).
- One example would be to respect their 60% quota when doing laundry. If a person typically does 4 loads of laundry on Saturday morning, they could cut it back to around 60% doing 2 loads. If one usually folds all

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<sup>&</sup>lt;sup>5</sup> Note that participants will mostly be 'underdoers' but that the group may also include some 'overdoers'. The former will need to increase and the later decrease their activity level. This distinction was discussed in more detail in Session 3.

<sup>&</sup>lt;sup>6</sup> Different OT's will have access to different devices where they work so this list of assistive devices may vary.

- their laundry in 30 minutes, but identifies that symptoms increase after this activity, they could use a timer and set it at 20 minutes for folding laundry (60 % of baseline). A rest break would be incorporated and activity completed after the brief rest period. After giving this example, ask participants to identify the principles incorporated. (Answer: Baseline setting, Activity and Rest Cycling)
- Next, ask the participants to get into pairs and ask them to come up with two more examples of how they would incorporate the use of devices described earlier (i.e. timer, pedometer, heart rate monitor) as well as some of the operant learning principles. Give pairs 5-10 minutes to complete this exercise. The participants will then reconvene to share ideas with the larger group

#### SMALL GROUP ACTIVITY – CHOOSING AN ACTIVITY

- Divide into subgroups of 3-4. Give each subgroup 10 minutes to complete this exercise. They are asked to
  - o (1) pick one activity that the group normally avoids or has limited participation in, and then
  - (2) ask them how they would adapt the activity using the pacing principles of operant learning.
- During this exercise, the subgroups will be provided with paper and pencils. One person per subgroup is to be the recorder. Participants are to think about how they would incorporate health-promoting devices along with principles of operant learning (activity-rest cycling, switching, using reinforcers, shaping, the Premack principle, assertive communication, etc.) into their activity.
- Once the subgroups have completed the exercise, the big group will come back together for 10 minutes.
   There will be one spokesperson from each group that will explain how they applied the strategies to their chosen activity.

#### **HOMEWORK**

# **ACHIEVING THEIR WEEKLY ACTIVITY GOALS**

- Ask them to use their handout 14 goals for week 2 and their weekly calendar to pre-plan their activity goals.
- First, they have to plan when they are going to do each activity on their list. It is important that they adhere as much as possible to their plan in order to maintain their routine.
- Second, they should maintain their activity, even when they feel an increase in pain and fatigue when doing
   it.
- Third, they should always take their pre-planned rest periods (but not extend them!) irrespective of pain and fatigue.
- It is important that participants understand that this homework is essential, even if they are reluctant to
  work when they have some increase in pain or fatigue. This exercise will allow them to gradually increase
  their activity level by pacing using time and quotas, as well as adequate rest periods to meet their goals and
  feel less disabled by their chronic pain condition.

# **OPERANT LEARNING SESSION 7**

**USING PROPER BODY MECHANICS: GROUP SESSION** 

#### **SESSION 7 OBJECTIVES**

# At the end of this session the participant will be able to:

- · Apply proper body mechanics to sitting, standing, sleeping, lifting, carrying, and reaching
- Generalize application of proper body mechanics to their daily activities
- Set up a computer work station so that it is ergonomically correct

#### **SESSION 7 MATERIALS**

- Session 7 handouts
- Flipchart
- Weekly operant learning group progress chart
- Materials for the practical component: (1) Computer work station: computer with keyboard and mouse, document holder, chair, desk, footrest, lumbar support, timer; (2) Sweeping floors: broom and dustpan (long and short); (3) Laundry: two boxes to simulate washer and dryer, clothes to fold and put away, chair, table, footrest, laundry bag, laundry basket; (4) Meal Prep: pantry, table barstool, footrest, recipe book with book holder, supportive footwear; and (5) Packing for a move: various sizes of boxes on different levels, items to put into boxes (i.e. books), table, chair.

#### **WEEK 6 HOMEWORK: FEEDBACK AND DISCUSSION**

- First, have the participants enter their information on the weekly group progress chart.
- When the charting is completed, take about 15-20 minutes to let the group participants discuss their experiences with the following:
  - o Did they meet all of their weekly goals? If not, what happened?
  - o Did they maintain their routine as scheduled? If not, what happened?
  - o Did they allocate times for their rest periods, and stick to the plan?
  - When using task switching, did they make sure it was determined by time or quotas that they set?
  - How did they manage the activity that they avoid the most? Did they use session 5 strategies (Premack principle, shaping, cues, safety behaviors, completing the task)?
  - How did they feel when they succeeded at their tasks? Did they reward themselves? Did they receive
    positive feedback or attention from others? Did they feel a sense of accomplishment? Did they feel
    that taking a rest period after the task was rewarding?
  - Over the week did were they more aware of their pain and fatigue behaviors? Which ones? Did they try to modify them? How? Did it work?
  - o During the week, did they receive intermittent reinforcement? Which ones?
  - o During the week, did they observe that they have used modeling? In which circumstance?
  - During the week, did they apply some of the activity pacing concepts? Which ones? Did they work?

- Make sure that all participants discuss everything they were supposed to do during their week.
- Reinforce their successes, and encourage the group to do the same.
- For those who did not meet their homework goals in all life domains, ask what happened in an empathic manner (so that they don't feel punished). If participants indicate that the pain and the fatigue stopped them from completing their goals, explain the importance of being proactive if they want to achieve their goals (without punishing them for not completing them). When participants do not meet their goal for 2 weeks in a row, the therapist should ask them to return to their previous goal and, from there, begin increasing again. If a participant does not complete their homework due to a lack of motivation, ask them how they are planning to achieve their (specific) goals and what they could do to address any barriers. Paraphrase adaptive goals and plans. Through this type of questioning and emphatic listening, help them to make a plan that they are confident they can follow.

# **TEACHING SESSION 7 (45 minutes)**

- Proper body mechanics can be an important strategy with which participants can achieve their goals using operant learning principles (i.e. activity/rest cycling and task switching). Good body mechanics allow the body to have good joint alignment and use large muscles during activities, which will help to promote activity participation. The biomechanical principles involve reducing the load or stress placed in the spine during various positions and when moving objects. The spine is composed of natural curves and it is important to maintain these curves during daily tasks. A healthy spine curves inward at the neck, slightly outward at the upper back, and inward at the lower back (resembling a "S" curve). These three curves balance each other to ensure that the pull of gravity is evenly distributed. The curves of the spine as well as the discs between the curves act like springs to help absorb shock. If the curves of the spine are increased or decreased, the muscles, ligaments, and joints have to work harder to support the weight of the head and body. There are several principles of good body mechanics that can be used in various daily tasks at work, home, and during leisure activities. By using their body correctly to do activities more efficiently, they will be better able to achieve their goals and increase the amount of time they can do an activity.
- <u>Sitting</u> (Handout 28): Maintaining proper body mechanics during sitting is important whether they are sitting at a desk or sitting at home watching television. Techniques taught to help maintain proper position during sitting include:
  - Place feet flat on the floor with knees bent at a 90° angle. Footrests can also be a helpful way to maintain good posture while sitting. Make sure the footrest is positioned so that knees are bent at approximately 90 degrees and level with the hips.
  - Chin in, earlobes over shoulder and hips. Pull shoulders back and lift the chest. Maintain the normal S-shaped curve of the spine.
  - Place buttocks at the back of the chair while maintaining a small space between the back of their knees and the seat of the chair.
  - The lower back must be supported. Look for a chair that has adjustable lumbar support (lower back support). A lumbar roll or even a rolled up towel or cushion placed behind the lower back will provide support.

- If a chair has armrests, make sure they are positioned to support the weight of the arms. Armrests in a
  proper position help the neck and shoulders to relax. Armrests should not be too high to make you
  hunch or too low to make you over reach.
- Maintain an upright position during sitting. To get up from a seated position, move forward on your chair with your feet shoulder-width apart, and if appropriate place one foot in front of the other. This technique will allow you to use your stronger leg muscles and minimize relying on upper extremity and back muscles.
- Keep in mind that even sitting in the "correct" position for long periods of time will eventually become
  uncomfortable. Use activity rest cycling and time-based quotas while doing activities while sitting.
   Switching tasks will also reduce the stress on the spine and help prevent muscle fatigue and stiffness.
- <u>Standing</u> (Handout 29): Start with good, low-heeled supportive shoes (i.e. runners) with good shock absorption, arch support, and firm heel counter. Proper footwear should be worn indoors as well as outdoors. Proper footwear helps to maintain proper body alignment of the lower extremity.
  - While standing upright, there should be an imaginary straight line that passes through your ears, shoulders, hips, knees and ankles.
  - o Keep your head up and chin in, with arms and shoulders relaxed.
  - During standing, place feet shoulder-width apart (weight spread evenly over both feet) with knees relaxed and bent slightly.
  - Abdominal muscles should be tight and buttocks tucked in to help to maintain the lumbar curve of the back.
  - Raise one foot on a stool, promoting tilting of the pelvis & minimizing excessive curve of the lower back (eg. while doing dishes, open the cabinet door under the sink and rest one foot on the ledge inside of the cupboard).
  - Change positions often this will help to relieve stress on your spine. With prolonged standing, gravity
    and fatigue pull the head and neck forward and the lumbar curve increases.
  - Consider doing some jobs sitting rather than standing, such as chopping vegetables and ironing clothes. A barstool is a good alternative to standing while working at counter height. Switching between sitting and standing can help increase amount of time spent on an activity.
- Proper positioning when lying down Sleeping (Handout 30): Same as our waking hours, the goal is to
  maintain a neutral spine, even while lying down. People tend to spend about one-third of their time in bed,
  so they can't ignore how their bodies are positioned during sleep.
  - Make sure you are sleeping on a mattress that is not too firm or too soft. You want to support your body while lying down, but want to avoid pressure points from a hard mattress or sagging from a soft mattress.
  - Sleeping on your side or back is recommended for maintaining a neutral position. Sleeping on your stomach twists your neck to extreme ranges of motion, which causes the back to arch placing stress on the spine.
  - The side and back are the best positions for maintaining a neutral position.
  - Place a pillow between your knees (for side sleeping) or behind your knees (for back sleeping). This will help keep your spine in the right position and help ease stress on the lower back.

- Thick pillows may cause too much neck flexion use a pillow that allows you to keep your head aligned with the rest of your body. You may want to try a cervical pillow or roll to help with neck and back alignment.
- <u>Lifting and Carrying</u> (Handout 31): Teach the group to use their stronger leg muscles for lifting bend at the
  knees and hips
  - Keep your back straight (keeping with your natural back curves) Do not bend back!
  - Maintaining a wide base of support will help your stability while lifting feet should be kept about shoulder width apart, with one foot placed slightly ahead of the other.
  - o Lift straight upward, in one smooth motion (no jerking).
  - o Tighten stomach muscles when lifting. The abdominal muscles will help you while lifting, and reduces strain on your lower back.
  - The best height for lifting is between the knees and chest carrying heavy objects and doing
    activities above the shoulder level creates an extra burden on the heart. Store heavy articles in the
    places easiest to reach; light articles in the high and low areas.
  - Stand directly in front of and close to the object turn to face the activity, which avoids muscular stress on the spine caused by twisting the body.
  - Before moving the object, be sure that it is not too large or too heavy test the load. Check the
    weight and make sure you can lift it safely. If not, you should ask for help.
  - Keep the object being lifted close to your body (i.e. parcel, laundry basket, grocery bags) hug the load.
  - The participants can gradually increase the load that they are carrying. For example, if they typically carry three bags of groceries at a time, they can reduce their load and carry two bags at a time (60% of quota). A rest can be taken and then they can return to carry the third bag. If they usually fill their laundry basket to the top when carrying, they can reduce the basket so that it is two thirds full and then take a break. Once tolerances are reached, they can fill their laundry basket up to three quarters full. Tolerances can be gradually increased.
  - o Pushing is easier than pulling or lifting It is easier to utilize your weight advantage when pushing.
  - Do not hold your breath while straining or lifting try to breathe normally through any exertions.
- <u>Use proper bending techniques:</u> Adjust work spaces, such as raising a tabletop, to eliminate awkward postures of bending over.
  - Elbows should be at around 90 degrees when sitting at a desk or standing at a counter. If doing heavy work, surfaces should be a bit lower and when doing light work, surfaces can be a bit higher.
  - Prevent bending and stooping by using long or adjustable handles on dustpans, brushes, shower mops and even paint rollers. You can also sit down when gardening – consider raised flower beds or window boxes to limit bending and stooping. Using a light duvet rather than several layers of sheets and blankets can also reduce the amount of bending while making the bed.
  - Planning ahead is also important to implement in applying proper body mechanics gathering all supplies that you need prior to starting a task or project, so everything is in one place, will help with task completion. For example, arranging garden supplies and tools prior to planting.
- <u>Keep nose and toes in the same direction, and stay within the imaginary arc.</u> (Handout 32): The imaginary arc is the arm's length in all planes. Demonstrate this arc to the group.

- Move your body close to the object you are trying to reach to avoid over reaching
- Position yourself squarely when reaching to higher or lower levels.
- o Keep nose and toes in the same direction twisting places excessive stress on the spine
- Moving your body close to the task (i.e. walk with the broom) and using a leg lunge technique will help to keep stress off the spine. This can also be done while performing duties such as vacuuming, sweeping, shovelling, or raking.
- Using a stable step stool is recommended when doing activities that are above chest level such as washing windows, painting, changing light bulbs, or hanging pictures.
- Rearrange your environment. Keep frequently used items in easily accessible places items not used frequently can be kept on higher shelves or in lower cupboards.
- <u>Ergonomics</u> (Handout 33): Ergonomics is the study of how to adapt the work place to the person. In other words the work environment should be adapted to the person, not the other way around. This is important because when the workstation fits a person's needs, fatigue and stress decrease while comfort increases. Here are some tips to keep proper posture when working at a computer workstation.
  - Monitor and keyboard should be placed directly in front of you, with the monitor at eye level. Look up and away from the monitor regularly, blinking your eyes, to reduce eye fatigue.
  - Position the mouse as close to the keyboard as possible. The mouse should be at the same level as the keyboard.
  - Keyboard should be positioned so wrists are neutral (not bent up or down or twisted). A wrist rest can sometimes be helpful in maintaining proper wrist posture.
  - o A lumbar roll or support should be used to provide lower back support.
  - Feet supported flat on the floor (a footrest may be needed).
  - Hips and knees should be at approximately 90 degrees.
  - Shoulders should be relaxed (not elevated) with forearms resting alongside the body
  - Elbows should be at a 90-degree angle when using the keyboard and mouse. Arms can be supported with armrests.
  - The monitor should be approximately arm's length away from the person typing.
  - Use a document holder to keep the neck in a good alignment when typing from a document.

# \* 15-MINUTE BREAK \*

# GROUP EXERCISE – APPLYING PROPER BODY MECHANICS TO HELP ACTIVITY PACING (Handout 34)

- 40 minute Practical Session: 5 Stations consisting of different daily activities will be set up for the group to rotate through. The group will be divided into pairs to rotate through stations. Take 5 minutes per station.
- The activity stations are outlined below as well as the supplies needed for each station.
  - o (1) Computer workstation (monitor with keyboard and mouse, document holder, different chairs with various supports, footrest, desk, lumbar support, timer).
  - o (2) Sweeping the floor (broom, dust pan).

- o (3) Packing and unpacking for a move (different sizes of boxes on different levels, table, items to put in boxes (i.e. books)).
- (4) Laundry (two boxes to simulate washer and dryer, clothes to fold and put away, table, laundry bag, laundry basket).
- o (5) Meal Prep (chair, table, barstool, counter-height table, footrest, supportive footwear).
- During the time at each station, the group is asked to come up with ways to do the activity while applying proper body mechanics. They are also asked to apply operant learning techniques that they have already been taught such as activity-rest cycling, task switching, assertiveness, awareness of pain and fatigue behaviors, Premack principle, rewards and positive reinforcement, using health promoting devices, etc.
- During this activity, the participants are asked to use shaping and reinforcement with their partner when
  doing the various activities (using good sitting, standing, etc.). The therapist will act as a model to
  demonstrate the task when demonstrations are needed. Participants are also asked to avoid pain and fatigue
  behaviors while doing the task and point out if their partner is doing these behaviors when participating in
  the task.
- Once each subgroup has rotated through the stations, the whole group will reconvene. Take 15 minutes to discuss the following:
  - O What principles of proper body mechanics were used?
  - O What straining postures were you able to avoid?
  - o What changes did you have to make (your technique / environment)?
  - o What other principles of operant learning could apply to these scenarios?
  - o What benefits did they experience when using operant learning and proper bodymenanics?

# In Closing...

- Pay attention to how sitting, standing, and lying postures can help you achieve your goals during an activity
- Alternate postures (switching) and take frequent rest breaks throughout daily tasks (activity rest cycling).
- o Rearrange your space or hang tools up so that everything is convenient and easy to reach.
- Keep within your arc and keep your nose and toes in the same direction when working on activities.
- Proper body mechanics are important for keeping the spine healthy. And it's easy to incorporate these
  principals into daily life. It may seem unnatural at first, but if one keeps up with it, the new positions will
  become routine.
- Remember your goals will be easier to achieve if you use your body wisely while performing daily activities.

#### **HOMEWORK**

# **ACHIEVING WEEKLY ACTIVITY GOALS**

 Ask the group to use their handout 26 goals for week 7 and their weekly calendar to pre-plan their activity goals.

- First, they have to plan when they are going to do each activity on their list. It is important that they adhere as much as possible to their plan in order to maintain their routine.
- Second, they should maintain their activity even when they feel an increase in pain or fatigue when doing it.
- Third, they should always take their pre-planned rest periods (but not extend them!) irrespective of pain and fatigue.
- It is important that participants understand that this homework is essential even if they are reluctant to work when they have some increase in pain or fatigue. This exercise will allow them to gradually increase their activity level by pacing using time and quotas as well as adequate rest periods to meet their goals and feel less disabled by their chronic pain condition.

# **OPERANT LEARNING SESSION 8**

**REACHING GOALS AND USE OF STANDARDS: GROUP SESSION** 

#### **SESSION 8 OBJECTIVES**

# At the end of this session the participant will be able to:

- Assess the level of importance of priorities and standards
- Pre-plan short, medium and long term goals using "SMART GOALS FORMAT" as a guideline
- Distinguish between physical limitations and pain, fatigue and avoidance behaviors

#### **SESSION 8 MATERIALS**

- Session 8 handouts
- Flipchart
- Weekly operant learning group progress chart

#### WEEK 7 HOMEWORK: FEEDBACK AND DISCUSSION

- First, have the participants enter their information on the weekly group progress chart.
- When the charting is completed, take about 15-20 minutes to let the group participants discuss their experiences with the following
  - o Did they meet all their weekly goals? If not, what happened?
  - o Did they maintain their routine as scheduled? If not, what happened?
  - o Did they allocate time to their rest periods, and stick to the plan?
  - When using task switching, did they make sure switching was determined by time or quotas that they set?
  - How did they manage the activity that they avoid the most? (Premack, shaping, cues, safety behaviors, completing the task)
  - How did they feel when they succeeded at their task? Did they reward themselves? Did they receive
    positive feedback or attention from others? Did they feel a sense of accomplishment? Did they feel
    that the rest period after the task was rewarding?
  - Did they apply principles of proper body mechanics during activities (proper sitting, standing, lying, lifting)?
  - Did they use any health promoting devices such as timers or pedometers to help with activity rest cycling and to help with gradually increasing participation in activities?
  - With their general weekly life activities, did they apply some of the pacing techniques? Which ones?
     Did they work?
- Make sure that all participants discuss what they were supposed to do during their week
- Reinforce their successes and encourage the group to do the same.
- For those who did not meet homework goals in all life domains, ask what happened in an empathic manner so that they don't feel punished. If participants indicate that the pain and the fatigue stopped them, explain the importance of being proactive if they want to achieve their goals (without criticizing them for not

completing the task). When participants do not meet a particular goal for 2 weeks in a row, the therapist should ask them to revert to their previous goal and begin increasing again from there. If a participant does not complete their homework due to a lack of motivation, ask them how they are planning to achieve their (specific) goals and what they could do to succeed. Paraphrase adaptive goals and plans. Through this type of questioning and emphatic listening, help them to make a plan that they are confident they can follow.

#### **TEACHING SESSION 8**

# **Maintaining priorities and standards (Handout 35)**

- At this point in the program, participants should have clarified their "real life" activity priorities ("Must do" and "Want to do"). Ask participants how they will approach tasks; are they high, medium or low priority? This strategy will help them to prioritize current tasks as well as those that they are planning for the following two weeks and over the following months. Priorities should balance "Must do" but also "Want to do" tasks. Over time, some priorities that were medium or low will move to higher priorities levels. It is important for participants to balance priorities in the context of the available time and changes that can occur in their lives from week to week.
- How well they know their priorities will determine the specific life activities/tasks that they will choose in order to fulfill their goals. Participants may have noticed that their priorities don't have to be based on how much pain or fatigue they feel.
- Standards are also related to priority-setting. Standards are usually considered when the participants set their goals. Standards can change throughout people's lives depending upon their priorities. For example, different people have different standards for housekeeping. For one person a spotless, tidy house is important whereas another person doesn't mind a bit of dust and messiness. Participants might want to think about their personal standards as a way to feel gratified when they accomplish something that will also improve their overall quality of life.
- When they are trying to reach and maintain some of their standards, some participants will have to make sure that they do not fall into a pattern of underdoing or avoiding the activity. Other participants will need to make sure that they don't overdo the activity in order to meet their standards. Achieving higher standards will be a gradual process and will occur as they slowly increasing their activity (i.e. by working at 60% under their baseline tolerance and by taking their goal-contingent rest periods). With time, they will be able to meet their (achievable) goals and attain their standards.
- It is important to note that their new pacing skills and the associated changes in their lives may have caused them to shift their priorities and standards. They might want to take time to reassess them before setting their goals for activities. For example, they may decide that housekeeping is now a lower priority and that they want to reduce their standards in that area because they would prefer to spend more time exercising or doing other "Want to do" activities. Even when using pacing techniques, there will still be a maximum number of things that they can reasonably accomplish in a day. Making sure that they use the available time to do the things that are most important to them is a key aspect of pacing.

#### **EXERCISE – STANDARDS AND PRIORITIES**

- Ask participants to share and discuss (around 10 minutes) (1) how their standards have changed or stayed over time and (2) the activities that are important to them now that they are doing pacing.
- Are these priorities and standards less pain and fatigue contingent? Have they noticed a positive change in their quality of life and their overall level of disability?
- Maybe some participants have already made changes to standards and priorities. If so, this would be a good opportunity to highlight how this new way of approaching activities has happened (e.g., less overdoing or underdoing, changing their standards to improve their quality of life, etc.)

# \* 15-MINUTE BREAK \*

### **TEACHING SESSION 8**

# Pre-planning short, medium and long-term goals: (Handout 36)

- To maintain a satisfying quality of life and to promote their pacing skills it is important that they set some short (2 weeks to one month), medium (one month to three months) and long (three months to one year) term goals that they want to accomplish in the future. Meeting these goals should also be rewarding. For example, Ann used to love to travel in Europe every year or two.
- Now that she suffers from pain and tires easily, she has given up travelling. Travelling was an important part of her quality of life. The goal of travelling can be made achievable if it is viewed from the perspective of activity pacing. The first step is to plan the trip. If she makes an itinerary in advance and if she spreads tasks out such as making plane reservations and booking hotels over a six-month period (breaking task into pieces), the goal becomes more realistic. If she decides to visit many countries per trip and rents a car she will need to make sure that she plans to stop the car every hour to rest and stretch (time-contingent rest) for 10 minutes. She may also decide to switch drivers when getting back in the car. Ann may also want to display less pain and fatigue to her travelling partner and to focus the conversation on the places that they are going to visit (communication). Ann will also plan activity/ rest cycling when visiting museums, and she will overcomes her avoidance of taking public transportation (she fears pain or injury if she is jostled by another passenger) by taking the subway (reducing safety behavior and escape-avoidance). She will ask support from her travelling partner (positive reinforcement) for her plan and for successfully taking the subway. When Ann confronts a pacing challenge, such as climbing stairs with her suitcase, she will try to problem-solve the situation by, for example, taking her luggage up a few steps at a time and resting periodically. Finally, Ann will experience naturally-occurring rewards frequently on her trip. These will include the positive experience of seeing new and interesting things, sense of accomplishment for continuing the trip, positive feedback from her travelling partner, and the rest periods that occur after doing specific activities.
- In many ways, Ann's trip is not very different than the trips she went on before she developed her pain and fatigue. However, the use of pacing skills enables her to achieve a long-term goal that she had considered unachievable. This example helps to illustrate the idea that participants can improve the quality of their lives

and be less disabled by their illness. It is important that participants identify their short, medium and long-term goals so that they can include them in their weekly goals schedule. Experiencing the benefits of using these strategies will help to motivate them to continue to implement these strategies in their daily activities and to do so more consistently.

- Goals need also to be ranked (high, medium, low) according to both their "Must do" and "Want to do" priorities.
- To help them formulate their goals, the concept of SMART GOALS (Doran, 1981; Meyer, 2003) (Handout 37) will be used. They are encouraged to make goals that are:

#### **SPECIFIC**

- Well defined goal: They must state their goal as specifically as possible.
- Ask themselves the questions, "who, what, when, where and how?"

#### **MEASURABLE**

They need to have a way to measure progress towards their goal.

#### **ATTAINABLE**

- Their goal should be meaningful to them
- Achievable and Action-focused

# **REALISTIC**

- Goals should be ambitious, but not impossible.
- Do not set them up for failure

#### **TIMELY**

- What kind of time frame are they looking at for each goal (short, medium, long)
- O When will they finish their goal or is it a lifestyle change?

# **EXAMPLE: Rest breaks during Gardening**

- SPECIFIC (eg. schedule rest breaks during weeding)
- MEASURABLE (eg. 5 minute break every 30 minutes)
- ATTAINABLE (eg. 3 times/week instead of once/week)
- REALISTIC (eg. Feasible as they have Fridays off during the summer)
- TIMELY (eg. Complete within 3 weeks)

# **EXERCISE – GOALS (Handout 38)**

- Ask the participants to take 20 minutes to complete their goal lists. (Handout 23 and 24)
- Ask them to share and discuss what their short, medium and long term goals are. What are their goal priorities? How do they plan to achieve these goals?
- Help them to try to make the SMART goals

#### **TEACHING SESSION 8**

#### Activity pacing in a more realistic way (Handout 39)

- They are starting to become "pacing experts." However they might be concerned about how to manage some of their physical limitations and their other comorbid health conditions (e.g. not able to bend their knees past a certain point, not able to lift more than 25 pounds, etc.). At this point, it is important for them to distinguish physical limitations from behaviors that are pain and fatigue contingent.
- If it hasn't already been done, physical limitations should be assessed by their treating physician or another health professional to clarify what they can do without causing tissue damage. Many individuals suffering from chronic pain and fatigue base their limitations on what they have been told not to do when they were in the acute phase of their illness (e.g., after a motor vehicle collision). However, as tissue damage heals and their pain becomes chronic a reassessment of limitations is necessary.
- Participants should ask their physician or health professional (e.g. in their next regular appointment) what they should consider to be "Don't dos" and then fill out **Handout 40**. They need to make sure they clearly understand any "Dont's". For example, if a participant reports having a bad problem with their knees, this doesn't necessarily mean that they cannot exercise or walk. It may just mean that they need to modify their exercises to take into account their condition. Knee osteoarthritis would be an example of this type of limitation.
- Participants might find that there is a fine line between physical limitations and avoid-escape behaviors. They may be surprised to discover that they don't have as many physical restrictions as they had thought. Consulting their physician so that they better understand their physical limitations is an important part of stopping escape-avoidance behaviors and increasing their activity level. Unless this aspect is properly addressed, they will remain fearful and will be less likely to participate in activities that will disconfirm their fearful expectations. Participants have to remember that physical limitations don't necessarily equal disability or a poor quality of life. Rather, they mean being aware of their physical limitations in order to set realistic weekly pacing goals which will improve their mood, disability and overall quality of life.

# **EXERCISE – OVERCOMING PHYSICAL LIMITATION (Handout 41)**

•	The group would be	e asked to take	2 minutes	to fill in the	e blanks to the	following sentence:

0	I have	problems/limitations, but can still do	

o Each participant is asked to come up with two examples.

- The participants are then asked to share what they have written and what they can still do despite having a deficit (15 minutes)
- This activity will help to show participants that despite the various limitations that their group members have, they can still perform many activities.

# **HOMEWORK**

#### **ACHIEVING THEIR WEEKLY ACTIVITY GOALS**

- Ask them to use the goals in handout 26 for week 8-9 and their weekly calendar to pre-plan their activity goals.
- First, they have to plan when they are going to do each activity on their list. It is important that they adhere as much as possible to their plan in order to maintain their routine.
- Second, they should maintain their activity even when they feel an increase of pain and fatigue when doing
  it.
- Third, they should always take their pre-planned rest periods (but not extend them!) irrespective of pain and fatigue.
- It is important that participants understand that this homework is essential even if they are reluctant to work after they feel a pain or fatigue increase. This exercise will allow them to gradually increase their activity level by using quotas (time and quantity-based quotas), as well as adequate rest time, so that they can meet their goals and feel less disabled by their chronic pain condition.

# **OPERANT LEARNING SESSION 9**

**GETTING BACK TO A NORMAL LIFE: GROUP SESSION** 

#### **SESSION 9 OBJECTIVES**

# At the end of this session the participant will be able to:

- Normalizing activity level
- Pacing when exercising
- Pacing in the workplace or when volunteering

#### **SESSION 9 MATERIALS**

- Session 9 handouts
- Flipchart
- Weekly operant learning group progress chart

#### **WEEK 8 HOMEWORK: FEEDBACK AND DISCUSSION**

- First, have the participants enter their information on the weekly group progress chart.
- When the charting is completed, take about 15-20 minutes to let the group participants discuss their experiences with the following
  - o Did they meet all their weekly goals? If not, what happened?
  - o Did they maintain their routine as scheduled? If not, what happened?
  - o Did they allocate time to their rest periods, and stick to the plan?
  - When using task switching, did they make sure switching was determined by time or quotas that they set?
  - How did they manage the activity that they avoid the most? (Premack, shaping, cues, safety behaviors, completing the task)
  - How did they feel when they succeeded at their task? Did they reward themselves? Did they receive
    positive feedback or attention from others? Did they feel a sense of accomplishment? Did they feel
    that the rest periods after completing tasks were rewarding?
  - o Did they manage their priorities and standards using activity pacing? How? Did this work?
  - During their weekly activities, did they plan goals using the SMART techniques? Which ones? Were their goals short, medium or long term?
  - During their weekly activities, did they apply some of the pacing techniques? Which ones? Did they work?
- Make sure that all participants discuss what they were supposed to do during their week
- Reinforce their successes and encourage the group to do the same.
- For those who did not meet homework goals in all life domains, ask what happened in an empathic manner so that they don't feel punished. If participants indicate that the pain and the fatigue stopped them, explain the importance of being proactive if they want to achieve their goals (without criticizing them for not completing the task). When participants do not meet a particular goal for 2 weeks in a row, the therapist

should ask them to revert to their previous goal and begin increasing again from there. If a participant does not complete their homework due to a lack of motivation, ask them how they are planning to achieve their (specific) goals and what they could do to succeed. Paraphrase adaptive goals and plans. Through this type of questioning and emphatic listening, help them to make a plan that they are confident they can follow.

#### **TEACHING SESSION 9**

## Normalizing activity levels (Handout 42)

- The main goals of the activity pacing program are to help participants re-establish normal levels of activity, increase their functionality, and improve their quality of life. Even though the main purpose is not to eliminate pain and fatigue, participants may experience a reduction of these symptoms. Some participants may experience overall reductions, or less peak pain severity and fatigue by pacing their activities. For those who do not experience these reductions, it is important to recognize the improvements that have occurred in their overall activity level, their sense of control over their life, and their quality of life. Ask them how their lives have changed since they began using these techniques. For most participants, pacing helps them to increase their activity tolerance without greater pain or fatigue. Being active becomes a strong reinforcer and it is assumed that the gains they have made will convince them that continuing to be active using these methods is a better option than returning to their old, less effective, coping strategies.
- Explain to the participants that by slowly increasing their activities every week, they will reach a point where they can't increase anymore. This is what we called a "ceiling effect". The "ceiling effect" means that they will decide, based on their "Must do" and "Want to do" activities, when they feel they have reached their maximum goal for a specific activity. For example, if they have met their weekly goal of cooking four dinners out of seven and want their spouse to contribute to meal preparation, they would decide to stop increasing this specific activity. However, it is important that they continue to cook on pre-planned days irrespective of their pain and fatigue levels. They also need to continue their activity/rest cycling (i.e. predetermine task switching and limited rest periods) to maintain their new activity level. In this example, it is expected that the satisfaction of cooking a good meal and their spouse's gratitude will be a strong enough reinforcer to help them maintain the behavior change.
- Normalizing activity levels also means to become more flexible, as their new pacing behaviors are well maintained over the long term. For example, they sometimes might want to go to a restaurant instead of cooking. But it is important for them to ask themselves whether this decision is pain or fatigue-related. Are they avoiding cooking because they are afraid their pain might increase or because they think their family would enjoy a dinner out? Normalizing activity is also related to their actual physical limitations, comorbid health conditions and age as well as their priorities, standards and goals. The activity pacing program is designed to help participants be more functional and to regain their quality of life. Every participant will differ in terms of what they consider to be functional, and what is an improved quality of life for them. For example, a participant who has been retired for many years and has many other health problems may consider that they have returned to normal functioning when they are able to go for a walk, participate in specific social activities, keep up with their housekeeping chores, and spend time with their grandchild. In contrast for someone younger who has fewer comorbid conditions, being functional and having a good

quality of life might mean going to work four days a week, taking care of his or her two children, and playing a team sport once per week.

#### **EXERCISE – NORMALIZING ACTIVITIES**

- Take 10-15 min to ask the group to share and discuss what they consider to be 'getting back to a normal life'? Which type of activities does this include for them?
- What about their overall quality of life? Are there things in their lives that have improved because they have been pacing? Which ones?
- What does being less disabled mean for them? Do they feel they can accomplish more and regain functionality?
- What are normal life rewards that could help them stay motivated?

#### \* 15-MINUTE BREAK \*

#### **TEACHING SESSION 9**

## Tips and benefits associated with pacing during exercise (Handout 43)

- At this point, participants have been exercising on a regular basis for more than two months. They have gradually augmented their activities to reach certain goals. Gradual increases can take many forms, such as speeding up (e.g. walking), increasing weights (e.g. heavier free weights), endurance (e.g. longer bike rides), flexibility (e.g. stretching), and balance (e.g. yoga). Participants have to track their progress when they are exercising in order to achieve their goals and see improvements over time. For example, if they are doing cycling, they could decide to work on exercise intensity by choosing a more challenging route. They could also do this by timing how long it takes them to arrive from A to B and decreasing that time, they might also choose to work on their endurance by increasing their number of kilometers that they travel. Devices, such as timers, speedometers, odometers and heart rate monitories could help them keep track of their progress and maintain their motivation.
- Exercising regularly has many benefits on the participants body, which include:
  - Lowering their body fat, helping them to reduce risk factors for conditions like diabetes, obesity and cancer
  - Improving their blood circulation, resulting in a healthy heart and blood vessels and a more efficient cardiovascular system
  - o Gaining more stamina, so that they use less energy to accomplish the same tasks
  - o Improving their flexibility, giving them a better ability to bend, twist and reach without injury, as well as improving their overall balance and coordination
  - o Strengthening and toning their entire body for greater strength and stamina and better posture
  - Improving their quality of life by reducing stress

- Improving sleep quality
- o Reinforcing their immune system, which helps them fight viruses and infections
- o Increasing their bone density, which helps reduce broken bones and osteoporosis risk
- o Etc.
- Gentle, slow, smooth, sustained stretching before and after exercising will help their muscles feel more comfortable and will increase their flexibility. They will also feel calmer and more relaxed after stretching, so this can also serve as a good rest period after exercising. Participants can also use stretching as a way to rest in other contexts such as when they are at work (e.g. stretching for 5 minutes after sitting for 30 minutes) and doing chores (e.g. stretching for 5 minutes after unpacking grocery shopping), etc.
- When exercising, it is also important that participants warm up by gradually building up the intensity of the
  exercise and then wind down at the end. They also might want to plan some short breaks (e.g. 15 sec) to
  drink water regularly during exercises.
- Some participants may still fear pain, fatigue or injury. It is important that they understand that some increase in discomfort is a normal part of beginning a new exercise program. They may want to remember how they felt after doing an exercise before their chronic pain and fatigue started. However, if participants experience unusual symptoms they should discuss it with the therapist at the end of this session, or with their treating physician.
- In the weeks that follow, participants will reach a point at which they will achieve their exercise goals. In general, exercise should be done at least 3 times per week, and last a minimum of 30 minutes. When they have reached this goal, they will have to maintain their motivation to continue exercising. To stay motivated they can use many types of reinforcement such as exercising with a friend for encouragement, planning to eat a snack after exercising, buying a new piece of sports equipment or clothing when they meet their short-term goals, etc. For some participants, exercising might also become very rewarding in and of itself. In this case, they may want to use the Premack principle. For example, they could reward themselves by going for a 30 min swim after they have completed their work day (i.e. assuming that exercise is a more desirable activity than going to work).

#### **GROUP EXERCISE - STRETCHING**

- Get participants to stand up, walk, and do stretches that they know are safe to do.
- Ask participants what they consider to be their maximum exercise goals. Do they plan to try other physical activities along the way? Which ones?
- What are the rewards that they want to put in place to help them keep themselves motivated over the next few months?
- Give the group 5 minutes to discuss these questions with the person beside them, and then have them come back together to share their ideas.

#### **TEACHING SESSION 9**

## Managing pacing when working (Handout 44)

- Participants may find that pacing is more challenging when they are at work (paid or unpaid), since there are some things they may not be able to control. However, it is important to clarify what is clearly not within their control and what they might perceive as uncontrollable. Sometimes there is a difference. They should be encouraged to use the strategies that they have learned in the previous sessions to control what they can.
- Tasks that are part of a regular routine (i.e. predictable) are easier to be broken into pieces and are more amenable to using rest and activity cycling, including task switching.
- Communication in the workplace is somewhat different than in their personal life with friends, family, and acquaintances. There are different expectations, issues, formalities and organizational hierarchies that they have to think of when they are communicating or dealing with colleagues, clients and superiors. They need to communicate their needs effectively (e.g., using limited rest periods when working) in a way that is task management oriented rather than pain or fatigue related. Many employers or types of jobs have some flexibility. Employees have to communicate what they want and/or use problem solving techniques to find solutions to managing at work. This problem solving includes changing the way job tasks are organized, using task switching, taking limited rest periods, improving ergonomics/body mechanics, using health promoting devices, varying work schedules, etc. Fear avoidance (but not documented physical limitations), can also be overcome and managed the same way. When applying problem solving in the workplace, it is important that the participants focus on the unique behavioral constraints and possible opportunities of the workplace.
- Participants that tend to underdo or overdo have to be careful about their work schedule (e.g. taking time off versus overtime) and their roles and responsibilities (e.g. taking a lesser role even if they have the competence).
- Participants might also want to think of their jobs from the point of view of short, medium and long term
  goals for career advancement, retirement planning, etc. Goals have to be planned according to achievable
  goals (e.g. working one day less per week to spend more time gardening) instead of how they feel regarding
  their pain and fatigue levels. Some participants with more physical limitations might decide to change their
  life style and reduce their work time, but they also need to feel that they are still functional and not overly
  disabled by the pain or fatigue.
- Positive reinforcement is applicable at the workplace in the sense that participants may receive positive
  feedback from their colleagues and superiors if they improve their work-related activity tolerance. They may
  also feel more satisfaction with their work, and improved self-worth.

## **GROUP EXERCISE (Handout 45)**

- Form small groups of 3-4 participants, where a minimum of one of the participants is presently working or volunteering. Take 10-15 min to do the following exercise.
- One participant from the group will be asked to describe their work (or volunteer) situation. This activity involves applying pacing strategies to work situations.

- Participants are asked to pre-plan a one-day schedule that includes work and rest periods. They are asked to
  write down the types of strategies that can be used to help pace each activity in their work/volunteer
  environment.
- Bring the group back together and ask one participant per group to share how they would use pacing in a specific work/volunteering situation.

### Explain potluck activity for session 10

- Discuss with the group that there will be a potluck on the last day. The group is encouraged to use activity
  pacing when preparing their food (i.e. taking limited breaks, pre-planning task-switching, using good body
  mechanics, using devices, maintaining their standards etc.).
- The group will be given approximately 10-15minutes to discuss what they are going to bring to the potluck.

#### **HOMEWORK**

#### **ACHIEVING THEIR WEEKLY ACTIVITY GOALS**

- Ask them to use their handout 26 goals for weeks 10-11 with their weekly calendar to pre-plan their activity goals.
- First, they have to plan when they are going to do each activity on their list. It is important that they adhere as much as possible to their plan in order to maintain their routine.
- Second, they should maintain their activity even when they feel an increase of pain and fatigue when doing
  it.
- Third, they should always take their pre-planned rest periods (but not extend them!) irrespective of pain and fatigue.
- It is important that participants understand that this homework is essential even if they are reluctant to
  work until they feel an increase in pain or fatigue. This exercise will allow them to gradually increase their
  activity by pacing using time and quotas as well as adequate rest time to meet their goals and feel less
  disabled by their chronic pain condition.

## **OPERANT LEARNING SESSION 10**

**MAINTAINING ACTIVITY PACING SKILLS: GROUP SESSION** 

#### **SESSION 10 OBJECTIVES**

### At the end of this session the participant will be able to:

- Understand the importance of maintaining consistent activity/rest cycling
- Manage setbacks and flare-ups in their use of pacing skills
- · Generalize pre-planning across all areas of their lives
- Combine different pacing strategies while engaged in activities

#### **SESSION 10 MATERIALS**

- Session 10 handouts
- Flipchart
- Weekly operant learning group progress chart

#### **WEEK 9 HOMEWORK: FEEDBACK AND DISCUSSION**

- First, have the participants enter their information on the weekly group progress chart.
- When the charting is completed, take about 15-20 minutes to let the group participants discuss their experiences with the following
  - o Did they meet all their weekly goals? If not, what happened?
  - o Did they maintain their routine as scheduled? If not, what happened?
  - o Did they allocate time to their rest periods, and stick to the plan?
  - When using task switching, did they make sure switching was determined by time or quotas that they set?
  - How did they manage the activity that they avoid the most? (Premack, shaping, cues, safety behaviors, completing the task)
  - How did they feel when they succeeded at their task? Did they reward themselves? Did they receive
    positive feedback or attention from others? Did they feel a sense of accomplishment? Did they feel
    that the rest period after the task was rewarding?
  - With their general weekly life activities, did they manage their work or exercise differently? How? Did it work?
  - With their general weekly life activities, did they apply some of the pacing techniques? Which ones?
     Did they work?
- Make sure that all participants discuss what they were supposed to do during their week.
- Reinforce their successes and encourage the group to do the same.
- For those who did not meet homework goals in all life domains, ask what happened in an empathic manner
  so that they don't feel punished. If participants indicate that the pain and the fatigue stopped them, explain
  the importance of being proactive if they want to achieve their goals (without criticizing them for not
  completing the task). When participants do not meet a particular goal for 2 weeks in a row, the therapist

should ask them to revert to their previous goal and begin increasing again from there. If a participant does not complete their homework due to a lack of motivation, ask them how they are planning to achieve their (specific) goals and what they could do to succeed. Paraphrase adaptive goals and plans. Through this type of questioning and emphatic listening, help them to make a plan that they are confident they can follow.

## Maintaining activity pacing: Getting back on track (Handout 46)

- Participants might find it hard to continue pre-planning their goals on a weekly basis in the long term. Most
  participants are likely to discontinue their use of their weekly schedules at some point. Although such
  interruptions are to be expected, how these setbacks (lapses and relapses) are managed is critical to
  establishing long-term use of pacing. There are times when one can have a lapse or relapse despite
  previously implementing pacing into their daily activities.
- A lapse is a small "slip" or a brief interruption of their self-management plan. If a treatment lapse is caught
  early, it is fairly easy to "get back on track". A relapse is a serious and prolonged interruption of their selfmanagement plan. When this occurs, people often give up entirely.
  - Examples of a lapse:
    - Over-exerting themselves doing chores in response to demands from others and feeling 'too busy' to use pacing strategies
    - Forgetting to pace themselves on a busy day or weekend
    - Being in a bad mood for 2-3 days, doing very little and focusing on pain and fatigue
  - Examples of relapse:
    - Prolonged avoidance of some of their weekly activities
    - Resuming a general overexertion/crash ('yo-yo') activity pattern for more than two weeks
- It is important to let participants know that setbacks (lapses and relapses) are a normal part of their pacing program. Having a lapse or relapse does not equal failure. If for some reason, they do not complete their weekly schedule for a while (e.g. vacation, death of a relative, illness, or lack of motivation), they should simply begin pre-planning weekly goals from where they left off. If they find that the activity level is too difficult since their body is no longer accustomed to that level of activity, they need to set up their weekly goal below their tolerance level (between 60% and 80%) and increase their (time or goal-contingent) rest periods for a while. However, they won't lose everything that they have gained or the skills they have acquired through the program. The sooner they resume using these skills, the sooner they will get "back on track" and see the benefits again.
- To help them resume their use of pre-planning skills, they should review their most recent schedule as a starting point. This review will remind them of the progress that they had made and will help motivate them to continue. Remind them that positive reinforcement such as resting, a sense of accomplishment, support and feedback from others, and rewards will also increase their functionality, quality of life and mood. If they feel that their lives are revolving around their pain and fatigue levels and that they start to feel more disabled, socially isolated and distressed, this setback might be an indication that they should get back to their pacing strategies. They can also ask themselves some questions that will highlight reasons for resuming their use of pacing: Did they experience more disability and enjoy their life less since they stopped pre-

- planning their weekly goals? Did pre-planning their weekly goals have a positive impact on their quality of life and their relationships?
- Despite setbacks (lapses and relapses), pre-planning activities with limited rest periods should now be part of
  their weekly routine. At this point, it should also be easier for them to use their schedule and it is likely that
  many activities are already at normal activity levels. These activities only need to be maintained in their
  weekly schedules whereas other activities still need to be increased over the next 3 months. It is also
  important for participants to continue challenging themselves by doing previously avoided activities during
  the next 3 months.
- There are two ways that they can manage their weekly schedules during the next 3 months. For those who have reached a normal level for most of their activities (80% or more), they might prefer to use Handout 47. Using this handout, they can add, change or continue to increase their weekly goals for specific activities. They should still complete their entire weekly schedule even for activities that have been well integrated. Continuing to schedule these activities will serve as a reminder to maintain their activities and reduce their chances of lapse/relapse. For activities that they are still in the process of developing, they may want to use the complete weekly plan (Handout 48) during the next 12 weeks. However, it is not a contest to see how fast they will reach their normal activity level; the most important thing is that they increase their activity level slowly every week and that they don't take more rest time than they have planned.

## Managing pain and fatigue flare-ups (Handout 49)

• It is likely that participants will experience pain or fatigue flare-ups related to factors outside of their control such as an acute illness (e.g., catching a cold) or a significant life stressor (loss of a loved one). Aside from the medically necessary rest, they should be encouraged to pace themselves and should continue their activities to the best of their ability. Instead of totally eliminating activities, they should determine what they can do and use the pacing skills that they have acquired to this point in the program. As they begin to feel better (e.g. the cold is gone) they can gradually increase their activity level and return to their regular pacing routine. If there has been a period of time during which they have relapsed, they should follow the lapse/relapse recovery process described above.

## **Review of pacing strategies (Handout 50)**

- Ask them to identify and describe the principles of pacing. Provide them with an opportunity to ask any questions that they still have regarding the use of pacing strategies.
- Use the review Handout 50 to briefly summarize the pacing strategies that they have learned throughout the activity pacing program. You can use one or two examples of every strategy using actual examples provided by the group participants in previous sessions.
- Highlight the importance of generalizing these strategies across their life domains (e.g. work, home, etc.).
- Remind them that the key to successful pacing is the <u>combined</u> application of different strategies in a flexible and creative manner. Remind them to ask themselves, when approaching an activity that is challenging: How

could I do this activity differently? Example: Gardening: It is much better to manage the activity (break up gardening tasks, use ergonomic tools, use good posture, speed up, increase tolerance, task switching) and then take a limited rest break.

#### \* 15-MINUTE BREAK \*

#### **GROUP EXERCISE: POTLUCK ACTIVITY**

- Allow about 15 minutes for participants to set out the potluck meal.
- Take 30-45 min to eat the meal. While participants are eating, encourage them to share how they used pacing to prepare their dish for the potluck. For example, they may have purchased a prepared salad dressing or made it themselves according to their standards but using activity/rest cycling. How did they use proper body mechanics while preparing their dish? Did they pre-plan and prepare their dish over more than one day? Did they meet the goals they wanted to achieve? Did anyone use other pacing strategies (e.g. task switching switching between cutting vegetables and stirring something on the stove)? How did they manage their limited rest time? In what ways did they find this activity positively reinforcing? Can they describe some reinforcers?
- Take this opportunity to reinforce progress and motivate participants to pursue their strategies for the next 3 months.

#### **HOMEWORK INSTRUCTIONS**

- Participants are expected to maintain their weekly scheduling chart over the next 3 months, until the first booster session is held. Ask them to keep track of any specific pacing problems during this period of time (e.g., use a highlighter to identify these on their chart).
- Remind them that even if they have setbacks at some point during the next three months, it is important that they attend the booster session because it will help them to overcome any difficulties.

## **BOOSTER SESSIONS**

There will be two booster sessions (one at 3 months and one at 6 months). These sessions are an important part of the pacing program and it is expected that participants will attend them so that they can review the principles taught in the Activity Pacing Program as well as to problem solve solutions to any challenges they have confronted. During these booster sessions, participants may also share with the group the many benefits that they have experienced while applying pacing strategies.

There will also be a 12-month follow-up session as a conclusion to the Activity Pacing Program. At the 12-month session, each participant will receive a certificate of completion for the Activity Pacing Program. At this time, refreshments will be served, and some time will be spent highlighting the participant's successes in applying pacing strategies.

## **OPERANT LEARNING**

THREE-MONTH BOOSTER: GROUP SESSION

#### THREE MONTHS BOOSTER SESSION OBJECTIVES

## At the end of this session the participant will be able to:

- Reflect on their personal successes
- Identify their barriers to implementing pacing strategies
- Manage set-backs (lapses and relapses) by using pacing strategies
- Further understand the importance of maintaining a consistent activity level using activity/rest cycling
- Challenge themselves to engage in previously avoided activities
- Further generalize pacing strategies to other life areas (e.g., exercise, chores, mental tasks, work, and leisure activities).

#### **BOOSTER SESSION MATERIALS**

- Handouts for 3-month booster session
- Weekly operant learning group progress chart
- Flip chart, markers
- Laptop for digital presentation of the material (optional)

## **FEEDBACK AND DISCUSSION (15 minutes)**

- Start by briefly giving the participants a chance to get reacquainted and discuss their experiences informally.
- Next, distribute Handout 51 Part-I and have participants complete the rating scales as indicated.
- Note: before the end of the session, make a copy of this form as reference for the 6-month booster session and return the original to the participants.
- Discuss factors that have contributed to improvements in their functionality and quality of life over the past three months.
- Discuss activities they were avoiding at the beginning of the pacing program and that they are now able to do. Reinforce their successes and accomplishments.
- Summarize this discussion by positively reinforcing the participants' overall progress. Emphasize improvements in their functionality and quality of life levels, and how they have been able to maintain their use of pacing skills (most of the time) for the past 3 months.

#### **REVIEW SESSION**

- Activity Pacing Principles/Strategies (Handout 52)
- Take 15-20 minutes to review the activity pacing principles.
  - Use the review handout (or digital slide) to briefly summarize all of the pacing principles and associated strategies that they have learned during the 10-week program.
  - o For each principle, ask for a volunteer to describe the principle and provide one or two examples of strategies they have used to apply the principle.
  - Highlight the importance of generalizing these strategies across their various activities of daily living
  - Remind them that the key to successful pacing lies in the application of a combination of different strategies, in a flexible and creative manner (THINKING OUTSIDE THE BOX).

#### FILLING OUT 3-MONTH BOOSTER FORM/GROUP DISCUSSION

- Distribute Handout **51 Part-II** and explain to the participants the purpose of the exercise. Give them 10-15 minutes to complete the questions.
- Tell the participants that answering the questions will give them an opportunity to reflect on their personal successes and any setbacks in using pacing strategies, as well as ways that they have overcome any challenges. Give a brief review of the definitions of lapse and relapse. A lapse is a small "slip" or a brief interruption of their self-management plan. If caught early, a treatment lapse is fairly easy to remedy in order to "get back on track". A Relapse is a serious and prolonged interruption of their self-management plan. When this occurs, people often give up entirely.

## Examples of a lapse:

- Over-exerting themselves doing chores in response to demands from others and feeling 'too busy' to use pacing strategies
- Forgetting to pace themselves on a busy day or weekend
- Being in a bad mood for 2-3 days, doing very little and focusing on pain and fatigue

### Examples of relapse:

- Prolonged avoidance of some of their weekly activities
- Resuming a general overexertion/crash ('yo-yo') activity pattern for more than two week
- The group discussion will give them a chance to share their problem solving strategies with their peers so that they can learn ways to tackle a challenging situation from each other.
- It is important to let participants know that setbacks (lapses and relapses) are a normal part of their pacing program. Having a lapse or relapse does not equal failure. If for some reason, they do not complete their weekly schedule for a while (e.g. vacation, death of a relative, illness, or lack of motivation) they should simply begin pre-planning weekly goals from where they left off. If they find that the activity level is too difficult and that their body is no longer accustomed to that level of activity, they need to set up their weekly goal below their tolerance level (between 60% and 80%) and increase their (time or goal-contingent) rest periods for a while. However, they won't lose everything that they have gained or the skills they have acquired through the program. The sooner they resume using these skills, the sooner they will get "back on track" and see the benefits again.

## \* 15-MINUTE BREAK \*

#### **DISSCUSSION SESSION**

- Use a flip chart or whiteboard to create two charts, as illustrated:
  - o Chart I: Most Successful Situation: What Helped/Associated Strategies & Tools, Benefits
  - Chart II: Most Challenging Situation: What May Help/Associated Strategies & Tools, Benefits

## **Example:**

Most successful pacing situation	What helped/Associated strategies & tools	Benefits
Applying pacing to laundry	Maintain activity — used proper body mechanics, divided task into sections, spread over two	Able to do this 'must do' task without over-exerting.
	days.  Scheduled activity and rest cycling/Kept to limits-Take small breaks (2 min) after going to the basement, start one load, sit to fold clothes, take a 5 min break, climb stairs with the load, take a small break (2 min), and put clothes away in the dresser.	Reinforcers Clean clothes, sense of accomplishement, maintenance of pre-pain laundry standards

Most challenging pacing situation	What may help/Associated strategies & tools	Benefits
Applying pacing to exercise (bicycling)	Avoidance — reduce fear avoidance. Use Premack principle, shaping (stationary bike before going outside), modelling (train with another person who suffers from a similar condition)  Schedule activity and rest cycling/Keep to limits —	Able to do this 'Want to do' task without over-exertion.  Learn that injury or excruciating pain are not a result of bicycling.  Increase strength and endurance.
	Schedule into weekly routine, 3 times a week starting with 5 min bicycling and a 2 min rest for a total of 15 min of bicycling. Increase slowly and start cycling outside.	Reinforcers Praise and support from the training partner, rewards by seeing progress using an odometer, more motivated to continue cycling.

- Starting with Chart I, give each participant 2-3 minutes to share their single most successful experience, and have them identify what worked and any associated strategies/tools that were used. Write out the answers on the chart. Note that other participants may have the same or similar answers and group these accordingly.
- Next, using Chart II, give each participant 2-3 minutes to identify their most challenging situation and list it on the chart. If the participant is able to identify a strategy that worked, have them indicate this. If not, then the

- group can help them by providing suggestions as to what strategies/tools could be tried. Again, if there are similar situations identified, group these answers accordingly.
- You may use the following questions to facilitate the discussion. (Note, questions may be placed on a presentation slide while participants are filling out Handout 51, to help them reflect when answering the questions; just change the phrasing to the second person ("you")
  - Have they successfully used pacing strategies in the past three months? What is their most striking activity pacing success?
  - o Have they tried but failed to use pacing strategies? What situations? What happened?
  - How did they manage the activity that they avoid the most? (Premack, shaping, cues, safety behaviors, completing the task)
  - o Did they maintain pre-planning of their weekly schedule and use activity/rest cycling? Were their activity quotas and their limited rest periods time-contingent?
  - Did they observe changes or improvements in the quality of their social interactions? What happened? (Diminished pain and fatigue behaviors, more positive communication, accepting more requests from others, etc.)
  - When they applied pacing strategies, what impact did they have on functionality, mood, and quality of life?
  - How did they feel when they succeeded at their tasks? Did they reward themselves? Did they receive
    positive feedback or attention from others? Did they feel a sense of accomplishment? Did they feel
    that the rest period after the task was rewarding?
- Summarize the results of the discussion, and highlight the benefits of pacing and the main strategies that were helpful in both the successful and challenging situations identified by the group. Note: *keep the charts and use as appropriate for the six-month booster session*.

#### **HOMEWORK INSTRUCTIONS**

- Participants are expected to maintain their weekly scheduling chart during the next 3 months. Instruct them to keep track of any additional pacing problems during this time.
- Invite them to complete Handout 53 to set up new activity pacing goals for the next 3 months.
- Remind them that even if they lapse or relapse at some point during the next 3 months, it is especially
  important that they attend the next booster session because it will help them further overcome any
  challenges.
- Instruct participants to keep track of any tips that have helped them succeed in maintaining some of the life style changes, to share with peers at the next booster session.

## **OPERANT LEARNING**

**SIX-MONTH BOOSTER: GROUP SESSION** 

#### SIX-MONTH BOOSTER SESSION OBJECTIVES

## At the end of this session the participants will be able to:

- Reflect on their personal successes and their barriers to implementing pacing strategies
- Further consolidate the principles of activity pacing and generalize its application to their daily activities
- Maintain lifestyle changes that incorporate pacing strategies & tools
- Feel positive about their progress obtained from the treatment program

#### **BOOSTER SESSION MATERIALS**

- Handouts
- Weekly operant learning group progress chart (to provide as needed)
- Flip chart, markers
- Laptop for digital presentation (optional)

#### **FEEDBACK AND DISCUSSION (15 minutes)**

- Start by briefly giving the participants a chance to get reacquainted and discuss their experiences informally.
- Next, distribute Handout 54 and have the participants make the appropriate ratings.
- Ask participants how their level of functioning, quality of life and use of pacing strategies are different than they were at the 3-month booster session. Provide them with the ratings they had completed at the 3-month booster session.
- Discuss the factors that contributed to changes in their functionality and quality of life levels, and their use of pacing strategies.
- Positively reinforce the progress that group members have made. Highlight participants' improvements in pain and fatigue levels and how they have maintained their use of pacing skills (hopefully most of the time) for the past 6 months.

## **REVIEW SESSION**

- o Take 15-20 minutes to review the activity pacing principles.
- Use the review Handout 55 (or a digital version) to briefly summarize all activity pacing principles and associated strategies.
- For each principle, ask for a volunteer (different volunteer for each item) to describe the principle and to give
  one or two examples of actual strategies that they have used associated with the principle.
- Highlight the importance of generalizing these strategies across their activities of daily living.
- Remind them that the key to successful activity pacing lies in the application of a combination of different strategies in a flexible and creative manner (THINKING OUTSIDE THE BOX).

## **DISCUSSION SESSION (20-30 minutes)**

## Content will vary depending on the needs of group

- Use the group's previous list of 'Most Challenging Pacing Situations' (from the 3-month booster session). Revisit these challenges and ask the participants to identify the principles and associated strategies/tools they have tried and what benefits they have experienced.
- Next, give each participant an opportunity to share their 'best tips' things that have helped them to successfully maintain the lifestyle changes that have enabled them to balance their work, rest and recreational activities. List these tips on a flip chart or whiteboard. (NOTE: Remember to keep these tips/quotes as they will be used again at the 12-month review session to review their progress).

## **HOMEWORK**

- Summarize the results of the discussion by highlighting their successes and providing encouragement to continue using their activity pacing self-management strategies.
- Remind participants about the 12-month review session. Let them know that certificates and refreshments will be provided.
- Encourage them to continue keeping track of any tips/specific strategies that they have found most useful. They can share these ideas with their peers at the 12-month review.

# **OPERANT LEARNING**

12-MONTH FOLLOW-UP: GROUP SESSION

#### 12 MONTH FOLLOW-UP SESSION OBJECTIVES

- To have participants further reflect on their activity pacing success stories and the lifestyle changes they have made incorporating these principles.
- To acknowledge the group members' participation and commitment to the program with a certificate of recognition (those not able to attend this session will have their certificate mailed to them).
- To give participants an opportunity to celebrate their achievements with a brief social gathering and complimentary refreshments. (optional)

#### **BOOSTER SESSION MATERIALS**

- Bristol/poster board or flip chart or a laptop for digital presentation/screen
- Certificates
- Refreshments (optional)
- Prior to the session, prepare posters with quotes/stories of participants' success experiences with photos if
  available (this material would have been collected at the 6 month booster session and/or sent in by
  participants prior to this last meeting). The posters will be displayed around the meeting room to showcase
  the success stories to everyone. Alternatively, a digital slide presentation can be developed and projected on
  a large screen or white wall to show the group's success stories/photos.

#### INFORMAL DISCUSSION SESSION

- Content will vary based on the group's needs. Allow for approximately 1 ½ 2 hours
- Give the participants a chance to get reacquainted and have them informally share their success stories.
- Informally facilitate the discussion as needed and highlight any relevant points/strategies shared.
- The focus of the session is to also allow the participants to learn from each other and help each other *problem solve* any persisting challenges.
- Certificates will be handed out, followed by the social and refreshments session.

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