Understanding Parkinson’s

4 Managing Parkinson’s
Parkinsons_1.0  Understanding Parkinson’s for health and social care staff

4 Managing Parkinson’s

This version of the content may include video, images and interactive content that may not be optimised for your device.

Copyright © 2016

Intellectual property

Unless otherwise stated, this resource is released under the terms of the Creative Commons Licence v4.0

http://creativecommons.org/licenses/by-nc-sa/4.0/deed.en_GB.

This course is produced by the UK Parkinson's Excellence Network. It was originally produced as a face-to-face workshop course and has been re-versioned for online study with the support of the Opening Educational Practices in Scotland Project. Details of everyone involved in producing and funding this course can be found on the Acknowledgements page.
Contents

- 4.1 Introduction
- 4.2 What are the three main ways to manage Parkinson's?
- 4.3 Who is in the multidisciplinary team?
- 4.4 What is medication management?
- 4.5 What are the main drug treatments for Parkinson's?
- 4.6 The importance of medication timing
- 4.7 Getting medication on time
- 4.8 What are the main issues related to Parkinson's medication?
- 4.9 A case study
- 4.10 What surgical options are available?
- 4.11 What other methods do people use to manage their condition?
- 4.12 Summary
- Glossary
4.1 Introduction

Having worked through Section 3 you should now have a general understanding of the possible communication and cognitive problems in Parkinson’s, how they can be managed, and your role in this. In the previous sections, you learned about what Parkinson’s is and studied in-depth information about motor symptoms and non-motor symptoms. We have also considered how you can support people with Parkinson’s to manage their condition. In this section we will look in detail at the ways in which Parkinson’s is managed. This section is important to build on your understanding and help you to support and manage people’s Parkinson’s as best you can.

In this section we look at the following questions:

- What are the three main ways to manage Parkinson’s?
- Who is in the multidisciplinary team?
What is medication management?
What are the main drug treatments for Parkinson’s?
Why is it important that people with Parkinson’s get their medication on time, every time?
What surgical options are available?
What other methods do people use to manage their condition?

Learning outcomes

The purpose of this section is to give you an understanding of the processes, procedures, methods, techniques and services used to manage Parkinson’s.

By the end of this section you should be able to identify and describe the following:

- the range of methods, practices and possible interventions used to support people to manage their symptoms
- common issues that arise when medication is not taken or given on time and the consequences of this
- common side effects of Parkinson’s medication and the consequences of these for people with the condition
- what can be done to lessen these side effects
the types of local, community and statutory agencies, support services, and networks appropriate to the person with Parkinson’s, and how to access these.

Video content is not available in this format.

View transcript - Uncaptioned interactive content

You can download this resource and view it offline. It may be useful as part of a group activity.
4.2 What are the three main ways to manage Parkinson’s?

The management of Parkinson’s can be divided into three main areas:

- access to a multidisciplinary team – this includes physiotherapists, occupational therapists, Parkinson’s specialist nurses, and speech and language therapists, among others
- medication
- surgery.

In this section we will look at each of these areas in detail.
4.3 Who is in the multidisciplinary team?

The multidisciplinary team provides expert, professional help to those affected by Parkinson’s. Cooperative health and social care is essential and can make a huge difference to a person’s quality
of life. Everyone with Parkinson’s should have access to members of the multidisciplinary team.

The Parkinson’s multidisciplinary team should provide a comprehensive service to patients and their carers from diagnosis to the palliative stage. Clinical guidelines and good practice recommend that referral to a therapist service is considered from the time at which Parkinson’s is first diagnosed and regularly at medical reviews every 6–12 months after that.

The support that people need will vary from person to person, and from time to time. But early intervention from a range of health professionals can help people to maintain their independence for as long as possible.

The following gives a brief overview of the role that different therapists can play in enhancing a person’s quality of life either at home or in residential care. It is important that you know who may be able to support you in caring for a person with Parkinson’s. If you think the needs of someone in your care have changed, you should report this to your manager. They can help you decide who is appropriate to contact. Or you may be one of this team and may need to refer to others.

**Occupational therapists**

Occupational therapists can help people continue everyday activities when they become difficult to do, so they can stay as
independent as possible. People take part in a wide variety of activities and tasks every day. Occupational therapy aims to reduce the impact of health problems on day-to-day life by helping people to remain independent, maintain their interests and adapt to changes in their abilities.

For people with Parkinson’s, even simple tasks and daily activities that they used to do automatically can become slower and more difficult to carry out.

Occupational therapy can help improve people’s ability to continue carrying out tasks such as fastening buttons and dealing with clothing, as well as eating and drinking. The occupational therapist will assess a person’s ability to carry out these activities and suggest ways to make them more manageable.

In addition, occupational therapists can help with motor problems, such as problems with walking. They can also suggest appropriate adaptations, aids or equipment to help people who are having problems getting in and out of bed, moving in bed, using steps and stairs, or maintaining balance.

**Physiotherapists**

Physiotherapists use physical treatments, including exercise, to help manage any stiffness in joints, and to restore muscle strength and mobility. In the later stages of Parkinson’s, the physiotherapist may focus on walking, posture and balance. They may also start to
work with family and carers as part of the treatment process, suggesting ways to prevent falls.

Physiotherapists will assess how Parkinson’s is affecting the person’s movement and function. This can be done whether a person is newly diagnosed, or has lived with the condition for some time. They can then recommend techniques to deal with the problems identified or appropriate exercise programmes to help a person with Parkinson’s improve or maintain fitness. Physiotherapists can also help people with Parkinson’s by providing advice on aids and adaptations.

Clinical guidelines recommend that physiotherapy should be available for everyone with Parkinson’s.

Parkinson’s UK worked with physiotherapists to produce the new Parkinson’s exercise framework. It recommends that exercise can substantially help improve symptoms. You can download it from the Parkinson’s UK website to help people with Parkinson’s keep moving.

**Speech and language therapists**

Speech and language therapists are healthcare professionals who specialise in all aspects of communication, from facial expression and body language to speech and communication aids. They can help people with the communications problems discussed in Section 3. Speech and language therapists can be extremely
helpful, so we recommend you speak to your manager as soon as possible if the person you care for is experiencing any of these problems.

Speech and language therapists can also give carers and family member’s strategies and tips to help a person with Parkinson’s to communicate more effectively. These may include simple things such as watching a speaker’s face while they are talking, and limiting background noise, such as sound from a television or radio. Speech and language therapists can also give advice on how to spot the signs that someone may be having problems eating or drinking. Other problems may include producing too much or too little saliva, causing dribbling.

Some speech and language therapists will have taken a special course, called the Lee Silverman programme, to help them work with people with Parkinson’s. Many people with Parkinson’s who have taken part in this therapy have found it to be very useful in maintaining their voice control for longer.

Clinical guidelines recommend that speech and language therapy should be available for people with Parkinson’s.

**Parkinson’s nurses**

Parkinson’s nurses have specialist experience, knowledge and skills in Parkinson’s. They play a vital role in the care of people
with Parkinson’s, including offering guidance on managing medication.

They can also offer information and advice to families of people with the condition and other professionals involved in a person’s care. As specialists in the condition, they can advise other health and social care staff, who may not have specific knowledge of Parkinson’s.

Can you find out if there is a Parkinson’s nurse locally? You could try contacting the Parkinson’s UK local adviser, who will know whether there is a Parkinson’s nurse in your area.

**Dietitians**

Dietitians can help if the person you care for has problems with their diet, for example if they are under or overweight, or have digestive problems, such as constipation.

**Who else is in the multidisciplinary team?**

- General practitioners (GPs).
- Parkinson’s specialists.
- Pharmacists.
- Practice nurses.
- Psychologists and counsellors.
- Social workers.
4.4 What is medication management?

Medication management is a key learning area for any professional working with people with Parkinson’s. Even if you don’t administer medication, it’s vital that you understand the importance of medication timing and the main issues around medication side effects, including impulsive and compulsive behaviour.

Medication is usually the main treatment for Parkinson’s. Some of these drugs work by replacing or mimicking the actions of dopamine, the chemical that is in short supply in the brains of people with Parkinson’s. When someone with Parkinson’s doesn’t get their medication at the time prescribed for them their symptoms become uncontrolled – increasing their care needs considerably. In rare cases, it can lead to more severe problems, such as neuroleptic malignant syndrome.

The drug regime for someone with Parkinson’s will not remain the same throughout the illness. As the condition progresses, doses can be increased and different combinations of drugs may be tried.
Someone with Parkinson's may take lots of different drugs. The timing of this medication is very important. If people are unable to take their Parkinson’s medication at the right time, the balance of chemicals in their body can be severely disrupted. This can make their Parkinson’s symptoms worse. You will learn more about the importance of medication timing in Section 4.6.

Part of your duty of care includes maintaining the dignity of those you care for. One aspect of this will be to support the person in maintaining their freedom and independence. This includes giving people control over when they take their medication.

It's good practice for an expert to carry out a medical usage review. If you are working in residential care, your resident’s GP, specialist or Parkinson's nurse should do this a couple of months after they have arrived. This will make sure that the medication is tailored to the patient’s current needs. These may be different from when they were at home.

**Actions to take**

- Make sure everyone involved in caring for a person with Parkinson’s knows how important the timing of Parkinson’s medication is.
- A person with Parkinson’s may have a medication diary, so check this regularly. Ask them how their symptoms change when they need medication.
• A pill timer is a box with sections for different doses. It may have an alarm that sounds when different doses need to be taken. Use pill timers or alarm clocks to remind staff whose medication is due at different times from set drug rounds.

• Where you can, encourage people with Parkinson’s to look after their own medicines. Some people are able and will prefer to self-administer medication. Reassure them that you will support this routine, and offer pill timers or reminders to help them.

• If the person with Parkinson’s can’t swallow tablets, report this to your manager or make a referral. Other forms of Parkinson’s drugs are available.

• It is important to note that it is dangerous to stop medication suddenly. If the person you are caring for is going into hospital to have an operation, the timing of their medication needs to be carefully planned.

• If you notice that someone has missed a dose of their Parkinson’s medication you should report this to your manager or take appropriate action yourself.

Think about your current practice regarding medicines management for Parkinson’s. Your role may be minimal or you may be involved in administering medication. Use your reflection log to write 150–200 words comparing the information and actions outlined here to your current practice.
How many of these actions have you taken in the past? Discuss with your peers when you took these actions or in retrospect when you should have.
4.5 What are the main drug treatments for Parkinson’s?

The person you are caring for may be taking one or more of the following types of drugs. Some of these are available in generic form as well as the branded options mentioned. Most people in the complex phase of Parkinson’s will be on some form of levodopa and/or dopamine agonists. Speak to their GP, specialist or
Parkinson’s nurse if you need more information about the drugs a person with Parkinson’s is taking.

**Levodopa**

Levodopa has been used to treat Parkinson’s since the 1960s and is still the most effective drug treatment for Parkinson’s. This drug is a chemical building block that the body converts to dopamine, the chemical that is lacking in the brains of people with Parkinson’s. Types include co-beneldopa (Madopar or generic form) and co-careldopa (Sinemet, Duodopa, Caramet, Lecado, Stavelo or unbranded form).

There are different forms of each drug. There is a dispersible form of Madopar that may be swallowed whole or dissolved in water. Madopar capsules should not be broken. There is no dispersible Sinemet, but Sinemet tablets can be crushed. Duodopa is an intestinal gel, which is pumped continuously through a tube that is surgically inserted in the intestine.

For details of controlled-release options, please make sure you read our booklet ‘Drug treatments for Parkinson’s’.

**Levodopa and protein**

For some people with Parkinson’s, protein (which is found mainly in meat, fish, eggs, cheese, beans and pulses) seems to interfere with how well levodopa is absorbed by the body. Because of this,
people you care for may benefit from taking medication 30 - 60 minutes before they eat a meal.

However, levodopa can sometimes make people feel sick. Eating a low protein snack (such as crackers) when they take their dose may help to reduce this side effect.

It is important that people do not stop eating protein altogether, as it is vital to help the body renew itself and fight infection.

Tests restricting the intake of daytime protein have been tried by people with severe Parkinson’s symptoms and, in some cases, they have shown an improvement in their response to levodopa. This is called a protein redistribution diet where protein is saved until the evening and is suggested as a recommendation in the NICE guidelines for Parkinson’s.

A person’s specialist or Parkinson’s nurse can advise on timing doses, and a dietitian can also provide advice.

Find out more in the Parkinson’s UK diet and Parkinson’s information.

**Dopamine agonists (oral)**

These drugs help to improve movement symptoms and are used at all stages of Parkinson’s. The most common examples include ropinirole (Requip, Requip XL or unbranded form), rotigotine (Neupro), and pramipexole (Mirapexin or Mirapexin PR).
The following dopamine agonists are not so widely used but you may still find the occasional person taking them: cabergoline (Cabaser or unbranded form), bromocriptine (Parlodel or unbranded form), and Pergolide.

**Dopamine agonists (injection or infusion pump)**

Apomorphine (APO-go) is given by injection or infusion pump. Usually this will be given by nurses trained by an expert. This medication can cause short-term nausea and sickness, so an anti-sickness drug called domperidone (Motilium) will also be given for at least two days when it is started.

**Glutamate antagonist**

Amantadine is the only glutamate antagonist that can be prescribed. It is used to treat tremor and stiff muscles. Amantadine is available as capsules or in syrup form.

**COMT inhibitors**

These include tolcapone (Tasmar), entacapone (Comtess) and Stalevo. COMT inhibitors are used with levodopa, slowing its natural breakdown to make sure that it reaches where it is needed in the brain.

Stalevo is a combination drug therapy in one tablet. In addition to carbidopa and levodopa (active ingredients in Sinemet), Stalevo
contains entacapone, a substance that enhances the benefits of levodopa.

**MAO-B inhibitors**

A MAO-B inhibitor can be used on its own in early Parkinson’s, or in combination with other drugs at all stages of Parkinson’s. Selegiline (Eldepryl, Zelapar or generic form) and rasagiline (Azilect) are often taken in the morning as they are stimulants, so they could keep people awake if they take them at night.

**Anticholinergics**

These include trihexyphenidyl (benzhexol), procyclidine (Kemadrin or generic form) and orphenadrine (Biorphen or generic form). Benzhexol, orphenadrine and procyclidine are available in liquid form.

---

Domperidone (Motilium) is the anti-sickness drug of choice to prevent and treat nausea and vomiting caused by levodopa.

Domperidone can cause heart rhythm problems (arrhythmias) in some people over the age of 60. If your client is taking this medication, you should inform your manager, who can talk to their specialist, Parkinson’s nurse or pharmacist. You should also
understand what the signs of irregular heart rhythms are. These can include feeling faint, breathless or dizzy.

Other anti-sickness drugs that are generally considered useful include cyclizine (Valoid) and 5-HT₃ receptor antagonists like ondansetron.

### Drugs to avoid

Some drugs can bring on Parkinson’s-like symptoms or interact with Parkinson’s drugs, They should be avoided unless they’re recommended by a specialist. For hallucinations/confusion, avoid:

- chlorpromazine (Largactil)
- fluphenazine (Modecate)
- trifluoperazine (Stelazine)
- flupenthixol (Fluanxol/Depixol)
- haloperidol (Serenace/Haldol)

For nausea and vomiting, avoid:

- metoclopramide (Maxalon)
- prochlorperazine (Stemetil) Domperidone

(Motilium) is the anti-emetic of choice to prevent and treat nausea and vomiting caused by Parkinson’s medication. This is available
orally or as suppositories. If an injectable or alternative anti-emetic is required, cyclizine (Valoid) may be considered.

For coughs and colds, avoid:

- preparations containing sympathomimetics (such as pseudoephedrine and ephedrine) with MAO-B inhibitors

This is because there is a risk of hypertensive crisis - high blood pressure, which in extreme cases can cause a stroke.

Vigilence is particularly required with the use of:

- antihistamines, especially cinnarizine (Stugeron/Arlevert) which if used long-term, can mimic Parkinson's symptoms
- antipsychotics

If these drugs are taken, they can cause people with Parkinson's to become very unwell and it can take them a long time to recover, even when the offending drug is stopped. It is important that you are aware of drugs that could harm the person you are caring for, even if you are not responsible for administering drugs.

Find out more in the Parkinson's UK drug treatments information.

**Pain relief**
Many people with Parkinson’s also take some type of pain relief medication for their symptoms. It is vital that pain relief is available as their Parkinson’s progresses, especially in the end-of-life phase. A person’s specialist or Parkinson’s nurse can help with this.
4.6 The importance of medication timing

Why is it important that people with Parkinson’s get their medication on time, every time? If people with Parkinson’s are unable to take their Parkinson’s medication at the right time, the balance of chemicals in their body can be severely disrupted. This leads to their Parkinson’s becoming uncontrolled – increasing their care needs considerably. This will mean that staff will need to do more for the person with Parkinson’s than would otherwise have been necessary. It can take someone with Parkinson’s a long time to get back to normal after this. Understandably, people with Parkinson’s may be very anxious about getting their drugs on time. These times will differ from person to person and may not fit in easily with drug rounds.

Parkinson’s UK run a campaign called ‘Get It On Time’ to highlight the importance of people with Parkinson’s getting their medication on time, every time. Further information is available on the Parkinson’s UK Get It On Time webpage.

Neuroleptic malignant syndrome

If any of the drugs used for treating Parkinson’s need to be stopped, it is important this is done gradually. Abrupt withdrawal of certain drugs can result, albeit rarely, in neuroleptic malignant syndrome. This is a very serious condition that may cause death.
from complications of the respiratory, cardiovascular or renal system. This is rare, but it does emphasise the importance of the Get It On Time message.

**Dopamine agonist withdrawal syndrome**

**Dopamine agonist withdrawal syndrome (DAWS)** happens when a person’s dopamine agonist treatment is stopped or reduced. This could be when a person is experiencing impulsive or compulsive behaviour as a side effect and needs to stop taking (or reduce the amount of) the medication causing the behaviour. Stopping or reducing treatment should always take place in consultation with the person’s specialist.

Symptoms of DAWS can include anxiety, panic attacks, depression, insomnia, irritability and drug cravings. To avoid this, people with Parkinson’s must get help from a healthcare professional and withdrawal must be done gradually.

**Dopamine dysregulation syndrome**

**Dopamine dysregulation syndrome** is an impulsive and compulsive behaviour when people start taking more medication than they need to control their Parkinson’s.

If someone is taking too much levodopa, this can lead to further side effects, such as severe involuntary movements (**dyskinesia**).
If this is suspected, you should get help from a healthcare professional.
### Exercise 4.1

We have just learned why it is so important that people with Parkinson’s get their medication on time, every time. Listen to these recordings of some members of Parkinson’s UK talking about their personal experiences of the consequences of not getting their medication on time.

Audio content is not available in this format.

View transcript - Uncaptioned interactive content

Audio content is not available in this format.

View transcript - Uncaptioned interactive content
Think about what you have heard and consider the impact on both the person with Parkinson’s and their families. Write down your thoughts in your reflection log – you may want to use the following questions as a prompt.

- What could have been done differently?
- What was the impact on the person with Parkinson’s and their family?
- What, if any, was the impact on the ward and ward staff?

View answer - Exercise 4.1
4.8 What are the main issues related to Parkinson’s medication?

Wearing off

When a person goes from having good control of their symptoms to having less control, it is called a motor fluctuation. This change can happen slowly or quickly and can happen with someone’s Parkinson’s drugs wear off before it’s time for the next dose.

If you believe your client is experiencing this, it is important that you report it. They may need to arrange for a medication review to make sure that the medication regime is the best that it can be for the person you are caring for.

Sometimes the effects of wearing off happen quickly – this is called ‘switching off’ or ‘on/off’.

People with Parkinson’s are described as being ‘on’ when their drugs are working and their symptoms are mostly under control. If a person with Parkinson’s goes ‘off’, it means their symptoms are not under control and it’s harder for them to move. Some people may stop moving altogether. Someone with Parkinson’s might change from ‘on’ to ‘off’ very quickly, like a switch. This can be due to their Parkinson’s, but this can also occur if a person has not been able to take their medication on time.

Side effects
We cannot list all of the side effects of Parkinson’s drugs here. But some of the drugs used to treat Parkinson’s can cause problems with movement, behaviour, thinking and memory. It may not be obvious that these problems are caused by medication.

Symptoms may include confusion and hallucinations (seeing, hearing, feeling or tasting things that aren’t there). The person you are caring for may not report them as problems, because they seem very real to them. It is important to have a medication review from their specialist or Parkinson’s nurse if you suspect that they have these side effects.

**Dyskinesia**

Dyskinesia is when people with Parkinson’s experience muscle movements that they can’t control. They may be caused by a combination of the condition and Parkinson’s medication. It is most common in people who have been taking levodopa for many years.

The involuntary movements can be jerking, twitches or spasms, and can affect any part of the body. The strength of dyskinesias can vary from mild to severe. To reduce dyskinesia, the only option is to reduce their medication dose. But if you cut the dose of levodopa, a person’s Parkinson’s symptoms may not be so well controlled and they may experience more wearing off. Some
people may choose to live with the dyskinesia rather than compromise their ability to take part in their usual activities.

People with dyskinesia use up vast amounts of energy and calories because of their constant movement. It is vitally important to look carefully at their diet to ensure that they are not at risk of becoming malnourished.

**Actions to take**

- Maintain a food and fluid diary to monitor the person’s intake.
- Monitor their weight.
- Talk to your manager if you have concerns about a person’s excessive weight loss or poor appetite. A dietitian may be able to advise.
You can download these resources and view them offline. They may be useful as part of a group activity.

**Impulsive and compulsive behaviour**

This is a side effect that affects some people taking dopamine agonists. However, it can affect people taking other Parkinson’s drugs too, including levodopa.

Impulsive behaviour is when a person can’t resist the temptation to carry out certain activities. These are often activities that give an immediate reward or pleasure, such as gambling, eating or shopping, punding (continually handling and sorting objects) or an increase in sexual thoughts, feelings and actions (hypersexuality). Often, people may demonstrate more than one of these behaviours.

This behaviour may lead to harmful social, financial or legal consequences. The person may carry out a particular activity without giving any thought to the future or to long-term consequences. For example, someone who has the impulse to shop might buy a new item of clothing, even if they can’t really afford it.

Compulsive behaviour is when a person has an overwhelming drive to act in a certain way, often repetitively, to reduce the worry
or tension that they get from their urge. Some people continue to act in this way, even if they no longer get any pleasure or reward from the activity.

In most cases, this behaviour is out of character for the particular person. Impulsive and compulsive behaviour can have a devastating effect on people with Parkinson’s and those around them.

*The impulsive and compulsive behaviour film* discusses this topic in detail. Although it is aimed at Parkinson’s nurses it will help your understanding of his topic.

**Actions to take**

- Make sure that people with Parkinson’s and their families know about this potential side effect of Parkinson’s medication. Also, make sure that they understand that these side effects can be managed effectively. You may encourage them to read our information sheet. Make sure any behavioural changes you are concerned about are reported.

- Listen to family members, friends and carers when they’re worried about someone with Parkinson’s, and make sure the person’s specialist or Parkinson’s nurse is aware of these concerns.
• Inappropriate sexual behaviour could be caused by hypersexuality. Make sure your manager is aware of your concerns. The person’s specialist or Parkinson’s nurse should be contacted.

• A client’s sexual behaviour may be environmental. They may require some privacy to masturbate to relieve sexual frustration. Staff should speak to their manager about what is the best course of action.

• Tell your manager if you think they’re taking too much of their medicine on purpose – this could be a sign of drug-related compulsive behaviour.
4.9 A case study

Case Study 4.1 Stephen Williams – my story

Stephen Williams was 42 when he was diagnosed with Parkinson’s. At the time, he was a successful company director with a six-figure salary. But impulsive and compulsive behaviour had a devastating impact on Stephen’s life, leaving him unemployed and homeless.

After his diagnosis, Stephen’s neurologist put him on a type of dopamine agonist. Stephen soon found that his lifestyle was changing. ‘I went from being very organised, in a routine, to being a crazy party man. My life was out of control and I couldn’t focus..."
on anything – I was thrill-seeking all the time. I wanted excitement and it didn’t matter how I got it – it could be gambling or sex.

‘My family started to question me, but I couldn’t admit I was spending my money on high-class prostitutes and gambling. To some, it just looked like I was enjoying the lifestyle of a well-off, recently single guy – I justified my own behaviour this way, too.’

But this behaviour started to have an impact on Stephen’s working life. He started turning up late, missing meetings and taking more and more time off. Eventually he lost his job.

‘It came to the point where my house was repossessed. I spent some time at my parents’, but they had to kick me out because I couldn’t be helped – I didn’t realise I had a problem. I was stealing from my dad. So I’d lost my job, my house, and my family. I moved to London, and things continued downhill. I was living in a homeless shelter and would spend every day shoplifting on Oxford Street in London.

‘I rang my parents and asked for help. They contacted my doctor and two weeks later I went to see him and told him what had happened. I’ll never forget his reaction. He put his head in his hands, lifted himself back up, and said how, in the previous few months, research had started to come out about how impulsive and compulsive behaviour can be a side effect of some dopamine
agonists. For some people, this can result in behaviour such as
gambling, hypersexuality, collecting objects and binge eating.

‘My specialist changed me on to Sinemet and we went from there. That was the first step in my recovery. The trade-off was that Sinemet didn’t work so well for my physical symptoms. My physical symptoms started to show, but at least I wasn’t gambling in the bookies.

‘Then came the pain of going bankrupt and rebuilding my life, bit by bit. My creditors wanted me to go to prison for fraud as I had been taking out loans for buying a new kitchen, but gambling with the money. My specialist was helpful and wrote character references for me. While he wouldn’t admit responsibility, he had a conscience. People ask why I didn’t change doctor, but it happened, and we’ve both learned from it.

‘My view of dopamine agonists is now quite balanced. I’m not completely against them. In 2010, I went on to apomorphine, another dopamine agonist, and I still take Sinemet. I’m getting great mobility. I have a balanced view of the whole issue. Dopamine agonists are a useful medication for many people with Parkinson’s, and can do a lot of good – but people with Parkinson’s, and all the health and social care professionals involved in their care, must be aware of the risk of side effects.’
Exercise 4.2

Work through the questions below – remember there may be more than one correct answer.

1. Why is it important that people should be able to self-administer their medication where possible?
2. Name one of the serious side effects of Parkinson’s medication being reduced or stopped abruptly.
3. What tools are available to help people remember to take their medication?
4. Name two of the drug types used in managing Parkinson’s.
5. Describe what being ‘on’ and what being ‘off’ means for the person with Parkinson’s, and those around them.
6. Describe three side effects of taking Parkinson’s drugs.
7. What action should you take if you notice these side effects in a person with Parkinson’s?
8. Name two of the drugs that can be harmful to people taking Parkinson’s medications.
View answer - Exercise 4.2
4.10 What surgical options are available?

Although drug treatments are the main way of managing Parkinson’s symptoms, there are some types of surgery available. Surgery does not cure or slow down the progress of the condition, but it can help some people control their symptoms. It is not suitable for everyone and is used to treat people whose symptoms can’t be controlled by drugs.

Deep brain stimulation is the main type of surgery used to treat the physical symptoms of Parkinson’s. It involves passing small electrical currents through electrodes that are permanently implanted in the brain. It isn’t a suitable option for everyone and, like any surgery, there are some risks involved. If your client has had this procedure you will need to be aware of how it works and how your client controls their symptoms. You may wish to talk about this with your client’s specialist or Parkinson’s nurse.
Case Study 4.2 Lindy Bradley’s experience of deep brain stimulation

Lindy was diagnosed with Parkinson’s in 1999, aged 55.

‘I had reached almost the maximum medication I could be given – but all these pills were losing their effect. Spasm in my legs were frequent and painful. I was unable to move or turn over in bed. I could no longer go out in the evenings because after about 8:30 p.m. I was unable to move – apart from the endless shaking and jerking, which made dinner with friends or going to concerts impossible.

‘The prospect of deep brain stimulation was daunting and not without considerable risk. However, the alternative was far worse and therefore it was an easy decision to make. I couldn’t go on as I was, not at 66 with four grandchildren I wanted to see grow up. I remember one evening at home when I couldn’t even crawl on the floor. I just lay on the floor and cried.

‘During the operation I was fully awake and they kept me talking. My head was fixed in a frame so that I couldn’t move and the surgeon drilled into my skull, standing behind me. The outcome of the operation seemed doubtful, but they went doggedly on for nearly seven hours until they were satisfied that they had got the electrodes deep enough into my brain. Afterwards when they
switched me on, nothing happened. But two weeks later they tried again, with success. Thank goodness!

‘My life is now as normal as it can be, even though I still have my wobbly moments and occasional falls. I can go out in the evenings again, and am able to sit still in concerts without feeling I have to apologise to the person sitting next to me for my wriggling.’
4.11 What other methods do people use to manage their condition?

Complementary therapies

Many people tell us they find that complementary therapies can help with posture, fitness, relaxation, social interaction and general wellbeing. Some people have found relaxation therapies to be particularly helpful, as stress can make the symptoms of Parkinson’s worse. Techniques used include acupuncture, Alexander technique, aromatherapy, art therapy, hydrotherapy, massage, music therapy, reflexology, tai chi and yoga.

It is important that a person speaks to their specialist or Parkinson’s nurse for advice if they are interested in trying complementary therapies to find out if they are suitable. This is particularly true of herbal medicines or any therapy that involves taking vitamins, as some of these might interfere with Parkinson’s
medication. It is also important to use a qualified complementary therapist – GP surgeries can often provide a list of local practitioners.

**Parkinson’s UK local advisors**

Local advisers provide confidential, one-to-one support and information for people with Parkinson’s and their families. They can signpost to local services, and provide details about benefits and help with the application process. They can also act as a supporting voice if people are having problems getting their needs assessed.

**Find the name and contact details of your local adviser.**
4.12 Summary

We have now looked in detail at the management of Parkinson’s focusing in the three key areas of the importance of the multisdisciplinary team, medication management and surgery. Whether you are directly involved in administering medication or not, you have seen why it is important that you understand key issues such as timing of medication. Hopefully you have considered how this information can help you improve your practice.

The following exercise will help you see the real impact medication timing has on people with Parkinson’s. It will also help you to use what you have learned throughout this course.

Exercise 4.3

First watch the video below.

Video content is not available in this format.

View transcript - Uncaptioned interactive content
You can download this resource and view it offline. It may be useful as part of a group activity.

Having watched Mel and Jean’s story, use your reflection log to answer the following questions.

1. What are the issues and challenges for the people involved?
2. What services or professionals might have helped in this situation?
3. What could you have done to help?

View discussion - Exercise 4.3

Now try the Section 4 quiz.

Well done – this is the last of the section quizzes. You will need to try all the questions and complete the quiz if you wish to gain a digital badge. Working through the quiz is a valuable way of reinforcing what you have learned in this section. As you try the questions you will probably want to look back and review parts of the text and the activities that you’ve undertaken and recorded in your reflection log.
Personal reflection

At the end of each section you will be given time to reflect on the learning you have just completed and what that means for your practice. The following questions may help your reflection process.

Remember this is your view of your learning, not a test. No one else will look at what you have written. You can write as much or as little as you want.

Use your reflection log to answer the following questions.

1. What did I find helpful about the section? Why?
2. What did I find unhelpful or difficult? Why?
3. What are the three main learning points for me from Section 4?
4. How will these help me in my practice?
5. What changes will I make to my practice from my learning in Section 4?
6. What further reading or research do I want to do?

If you have the opportunity to be part of a study group you may want to share some of your reflections with your colleagues.

Now that you’ve completed this section of the course, please move on to Section 5.
Glossary

compulsive behaviour
When a person has an overwhelming drive to act in a certain way, often repetitively, to reduce the worry or tension that they get from their urge.

dopamine agonist withdrawal syndrome (DAWS)
A syndrome that occurs when a person's dopamine agonist treatment is abruptly stopped or reduced.

dopamine dysregulation syndrome
When a person takes more medication than they need to control their Parkinson’s. A form of impulsive and compulsive behaviour.

dyskinesia
Involuntary movements, often a side effect of taking Parkinson’s medication for a long period of time.

impulsive behaviour
When a person can’t resist the temptation to carry out certain activities.

motor symptoms
Symptoms that interrupt the ability to complete learned sequences of movements.

neuroleptic malignant syndrome
A rare syndrome caused by abrupt withdrawal of some Parkinson’s drugs. Can cause death from complications of the respiratory, cardiovascular or renal system.

non-motor symptoms
Symptoms associated with Parkinson’s that aren’t associated with movement difficulties.

wear off
This is where a Parkinson’s drug becomes less effective before it is time for a person’s next dose. This may cause you to go ‘off’.
Exercise 4.1

Answer

What could have been done differently?

- Hospital staff should have listened to the person with Parkinson’s and their husband or wife.
- Hospital staff – including doctors – should have had training on Parkinson’s and the importance of medicine management.
- Patients who are able should have been allowed to self-medicate.
- Ward staff should have sought help from a Parkinson’s specialist when the person’s condition was getting worse.
- A system should have been introduced so that Parkinson’s nurses are notified when a person with Parkinson’s is admitted.

What was the impact on the person with Parkinson’s and their family?

- Their symptoms were left untreated.
- Their condition got worse – for example, they were experiencing hallucinations.
- The whole family experienced anxiety and distress.
The person with Parkinson’s spent a longer time in hospital and had a longer recovery period.

What, if any, was the impact on ward and ward staff?

- Ward routines were severely disrupted.
- Patient appearing difficult and possibly showing signs of dementia.
- The patient needed much more care from staff.
- The situation caused anxiety for staff who were concerned that the patient was not receiving the correct care.

Back to Session 7 Activity 1
Exercise 4.2

Answer

1. It is important that people can self-administer their medication where possible because they can then make sure they are taking their medication on time. The timing of medication is crucial to people living with the condition. If people are unable to take their medication on time, their Parkinson's symptoms become uncontrolled. This increases their care needs considerably. If a person with Parkinson's goes into hospital or respite, it is important that they are allowed to continue their medication regimes.

2. Serious side effects include neuroleptic malignant syndrome or dopamine agonist withdrawal syndrome (DAWS).

3. Tools include pill timers, pill boxes with ringtone reminders, alarms on mobile phones, etc.

4. Drug types used in managing Parkinson’s include levodopa, dopamine agonists, MAOB inhibitors, COMT inhibitors, glutamate antagonists and anticholinergics.

5. Being switched ‘on’ means the person’s symptoms are controlled; they are able to function well, move around and manage everyday tasks themselves within their
own capabilities. Being switched ‘off’ means their symptoms are not under control; they may be unable to move or speak and can become quite distressed.

6. Side effects include nausea and vomiting, confusion, hallucinations, sleepiness and dyskinesia, and impulsive and compulsive behaviour. To check other side effects that you may have known about but are not mentioned in the workbooks, see the ‘Drug treatments for Parkinson’s’ booklet.

7. Make sure that the person with Parkinson’s sees their specialist or Parkinson’s nurse – they may be able to alter the person’s drugs regime to combat these side effects.

8. Drugs that can be harmful to people taking Parkinson’s medications include:

   - chlorpromazine (Largactil)
   - fluphenazine (Modecate)
   - perphenazine (Fentazin/Triptafin)
   - trifluoperazine (Stelazine)
   - flupenthixol (Fluanxol/Depixol)
   - haloperidol (Serenace/Haldol)
   - metoclopramide (Maxalon)
   - prochlorperazine (Stemetil)

Back to Session 9 Activity 1
Exercise 4.3

Discussion

1. What issues and challenges are they living with?
   - Not getting medication on time.
   - Lack of understanding from ward staff about how important it is that people with Parkinson’s get their medication on time.
   - Ward staff not listening to the person or their carer when they tried to explain.
   - Ward staff not understanding that the behaviour of the person with Parkinson’s was because of not getting their medication on time.
   - Stress and anxiety for both the person with Parkinson’s and their partners.
   - Experiencing hallucination and paranoia.

2. What services or professionals might have helped in this situation?
   - Staff training.
   - A willingness by staff to accept that the person and their carer might know best how to manage their Parkinson’s.
   - Earlier intervention from the Parkinson’s nurse and/or their specialist.

http://www.open.edu/openlearncreate/course/view.php?id=2161
• Agreement before the person went into hospital about self-medication or agreement regarding timings of medication.
• Physiotherapy staff and occupational therapists having an understanding of Parkinson’s.
• An advocate for the carer (that is, a Parkinson’s UK local adviser).

3. What could you have done to help?
• Reminded nursing staff about the importance of medication times.
• Supported the person and carers to speak to ward staff.
• Listened and reassured both the person with Parkinson’s and their carer.

Back to Session 12 Activity 1
Uncaptioned figure

Description

A woman holding a timer box.

Back to Session 1 Figure 1
Uncaptioned figure

Description

Two Parkinson’s experts conferring over some paperwork.

Back to Session 3 Figure 1
Uncaptioned figure

Description

A woman writing notes, talking to an older man.

Back to Session 5 Figure 1
Uncaptioned figure

Description

An older man is standing on a bridge over a river. He is facing the camera and smiling.

Back to Session 9 Figure 1
Uncaptioned figure

Description
An older woman with her face resting on her hand is smiling at the camera. She is wearing a red jumper.

Back to Session 10 Figure 1
Uncaptioned figure

Description

Two elderly women are sitting on chairs beside each other, with one arm raised. There is a row of people sitting behind them doing the same thing.

Back to Session 11 Figure 1
The different ways that Parkinson’s was managed prior to me taking the course was a mystery. I knew very little actually. I knew that there was a Parkinson’s nurse about somewhere. I didn’t realise that she is one of very few.

I didn’t realise that there was a whole multidisciplinary team working together with Parkinson’s. It was a whole new world. I realised that there’s so many support agencies out there that can be tapped into. It was phenomenal actually. It was quite exciting to see that you’re part of a much bigger team.

I think the biggest impact that doing the course has had for me has been the critical element of the person managing the medication, taking it on time, all the time. The effects of not having the medication on time, maybe the effects of having too much medication. The routine that they have to keep in taking the medication is so key to them being much more able, not dipping, having a much more active life. Also, working with the families, because even some families weren’t aware of the impact of taking medication on time, all the time.

Before I did the course, some of the side effects of medication that I knew about were the control of the tremor. That’s a good side effect of the medication.

One of the negative side effects I did know was compulsive-obsessive behaviour, which can manifest itself in many different ways, so people have to do certain things to achieve certain ends, or they might have a fixation on something. So kind of diverting that fixation was something that I was aware of.

Since doing the course I have learnt of other side effects of the medication, such as
dizziness, the drop in blood pressure, sleepiness, compulsive behaviour, involuntary movements, memory, some behavioural aspects. They were new. Some cognitive problems, memory problems. What I would do now, in particular, knowing some of these side effects with, say, the drop in blood pressure, if a client has been sitting for a while in a morning session doing an activity that hasn’t been active, who’s maybe reading the papers or something, what I would do now is before rising from a seat, do some simple chair exercises so that the blood’s moving. And when they’re now going to rise from the seat, they’re not going to have a dizzy spell and maybe fall back in the chair or something like that. Just to get them moving.

Before I did the course, I wasn’t aware that there was a multidisciplinary team. So, once again, my eyes have been wide opened. There’s a huge multidisciplinary team. And we all work together. There’s the speech and language. There’s physiotherapy. There’s the doctors, Parkinson’s nurses, day-care. There’s the Parkinson’s UK drop-in centre. There’s so much out there. Working with Parkinson’s UK, working with the Parkinson’s nurse, working with the CPN has enabled this man to stay at home. At the moment, he’s on respite. And what they’re talking about for him now is, OK, we need to keep you at home. We need to keep you coming to daycare. Because the difference in his mental health, his physical health, is so much better, just for the fact that tweaks have been made to when he takes his medication, how he takes his medication. It has to be before food so that it’s the most effective. You know, if you give it to him with his lunch, you might as well not give him his medication.

Just these little things are having such a major impact. And this man has gone from being stooped, depressed, sad, hopeless to having a life, going out walking, bowling, seeing his friends, enjoying his music. His life has changed.
I suppose there’s a kind of an unwritten, unofficial peer support that goes on here between the clients who live with Parkinson’s. They all know each other. If they didn’t know each other before they came here, they get to know each other. And they recognise the Parkinson’s in them. And you see them supporting each other, saying, oh, you’re wanting to get up? And they might not be able to help that person to get up, but they’ll, maybe at the lunch table, somebody’s needing something. They’re starting to drool, get a tissue. They look out for one another. But also there is a Parkinson’s UK group which they go to. And they’re so much more, I think, probably relaxed with one another, because they don’t have to explain themselves.

[Music playing]

Back to Session 1 MediaContent 1
Uncaptioned interactive content

Transcript

Margaret
I’ve been in hospital quite a number of times over the last two years. The first time I was taken into hospital, it was with a hip dislocation and once the hip had been rectified and I was back in bed, I became aware that I hadn’t had my Parkinson’s drugs.

Graeme
I was told to go home and therefore, unbeknown to me, they confiscated her drugs. And I seriously mean that they confiscated them.

Margaret
It left me feeling I was lying in bed, about three inches off the bed. My tremor was very bad

Graeme
And I couldn’t believe the story I was told, that after she had come out of theatre at 3 a.m., she asked for her Parkinson’s drugs and they wrote up the record sheet at the end of the bed: ‘Patient asked for Parkinson’s drugs – refused – signed, House Officer’.

Margaret
Well I did cheat terribly, and I got my family to bring in a selection of the drugs from home and I taped them to my shoulders, so that when I felt I needed extra drugs, I could take them. I got them that way.

Graeme
I found out subsequently that medical staff were of the opinion that lay people were not competent to give Parkinson’s drugs. They ignored the fact that for something like 20 years she had been self-medicating

Margaret
It wasn’t until the Parkinson’s consultant came into the ward that I was given the drugs that I needed.

Graeme
And I felt very, very angry on the occasion where the drugs were withheld, and yet there were drugs prescribed by that hospitals’ Parkinson’s consultant.

Margaret

However the last time I was in [hospital], I was told right at the start that I would self-medicate, and that was a completely different experience. It was better in that I had the responsibility for my own drugs. I knew what they were, I knew what I was doing, I knew when I needed them. I think I recovered faster through that. I was certainly much more comfortable.

Graeme

On her last admission to hospital for a further hip replacement, the staff were well aware that she was going to self-medicate. They were very relaxed about this and therefore, I was too.

Margaret

To get your drugs on time and know that you are in control of that, you feel like a human being and not a gibbering idiot.

Back to Session 7 MediaContent 1
Uncaptioned interactive content

Transcript

Mel went into hospital; he had his surgery; it was fine. I got a phone call, and it was Mel, and he said ‘Are you in that house?’ And I said yes. ‘Well I’m in this ward,’ [he said,] then he hung up. And I went in to visit him that night and he was totally out of character, nothing like Mel at all. Everybody that walked past the bed, he was shouting at them and waving, and – nothing, nothing like him. [To Mel] Was it? Well, you don't remember that bit.

And I went to the staff nurse in the evening and I said, there’s something not quite right – there’s something different about Mel. ‘Oh, Mel’s fine, he’s had his medication on time, there’s nothing wrong with him at all.’

Well the next day I went in, and what a shock. Mel was asking me to bring him earmuffs in. ‘They’re hiding you in these cupboards, they are controlling me and telling me not to look for you. They’re playing that music and it’s putting me off, this music and, I’m getting out of bed to look for you because I know you’re here.’

So I phoned the next morning at 6 o’clock in the morning, spoke to the staff nurse and asked how Mel was. And she said, ‘Mel says he’s had a hell of a night and he’s in tears, and he wants to know where you are. And we’re trying to tell him you’re not here, but he says you are – [and that] we’re hiding you, to prove to you that
He’s too violent to live with. And he’s trying to climb out of bed, and we can’t keep him in, and he just had a hip replacement. Please come to the hospital to visit as soon as you like and stay as long as you like.’

So I did, for five days. I left home at 10 in the morning and I got home at 10 at night. And these five days, I kept saying to Mel, ‘Don’t worry, this is gonna pass, this is gonna pass, you’ll be fine, you’ll be fine.’ But I don’t think I believed it myself, to be honest.

And for five ... **tortuous** days, I really thought I’d lost Mel – that he’d gone. And then he said to me one day, ‘They’re gonna shoot me tomorrow. They’re coming here to shoot me – because I’m too violent to live with you, so I won’t be coming home again.’

So I went to the staff nurse and I took Mel’s medication list with me, and I said ‘There’s something so wrong, I don’t know what it is, but this is Mel’s medication list – are you sure that it’s right?’ ‘Oh,’ says she, ‘I think the timing’s not quite right – the dosage is right, but the timing’s not quite right.’

The next day, the phone rang and a voice said, ‘I’m back in the land of the living.’ And you just could not believe what that was like. So that was a big lesson for us about how much difference one wee tablet can make.

**Back to Session 7 MediaContent 2**
Uncaptioned interactive content

Transcript

Subject

Sometimes I feel like I’ve been on the go all day. And you’re just totally washed out. But I don’t know. You just keep going.

Interviewer

I know, Ron. It’s hard, though, isn’t it?

Subject

Some days.

Interviewer

Mm-hmm.

Narrator

Dyskinesia is an involuntary movement caused by long-term use of Parkinson’s medication.

Subject

Concentration is like seeing in your interest. Sometimes you see an interest in things. I don’t know what I’ll do.

Interviewer

I do that too.

Subject

See, I used to go swimming and bowling on a Monday. And then I went singing on the Tuesdays singing on the Wednesday. And there was always something. [Inaudible] You know what they say?

Interviewer

Mm-hmm.

Subject

So I had something nearly every day. See the family at the weekend. I just kept busy.

Narrator

The medication contains Levodopa. Ronnie is well aware of the effects of the medication itself.

Interviewer

How long would your medication last then?

Subject

Well, that’s after two just now, you’ll probably find that take about, generally, about, nearly an hour. But occasionally, maybe 15 minutes.

Interviewer

No, but you want to keep them for ...

Subject

I'm trembling because it gives me the same effect. You get dyskinesia, with your tablets if you got too much in your system. I get this and involuntary ...

Interviewer

So, it can make it worse if you have too much medication.

Subject

Yeah, you've got these involuntary reactions because your body's full of chemicals.

Interviewer

Yeah.

Subject

And I just try and keep my steady. One every four hours or something. I could come down those stairs in half an hour's time and be gone.

Interviewer

Mm-hmm.

Subject

It's because the way it is now doesn't mean it ...

Interviewer

No, no.

Subject

I wish I could get rid of this. It's gonna take a few weeks. The pain is [INAUDIBLE]. It's still sore, back and legs. I was ready for it to go. And I fell.

Interviewer

And you fell.

Subject

And I made it worse. I fell about six times. And [Inaudible].

Interviewer

Have you?

Subject

And that's the only times I've ever fell.

Interviewer

And in the house?
Interviewer: [Inaudible].

Subject: Outside?

Interviewer: I think it was I was trying to stop using a stick. I think it was because I lost my balance.

Narrator: Not only is it tiring, but it can be embarrassing and cause weight loss.

Interviewer: I’m tired watching you.

Subject: A lot of people say that.

Interviewer: And you don’t get tired, you were saying.

Subject: Well, I get tired with this.

Interviewer: Yeah.

Subject: I don’t get tired of getting up early.

Interviewer: No.

Subject: There’s some nights I feel like I’ve been on the go all day.

Interviewer: Mm-hmm.

Subject: And you’re just totally washed out. But I don’t know. You just keep going.

Interviewer: I know, Ron.

[Music playing]

Back to Session 8 MediaContent 1
Uncaptioned interactive content

Transcript

Narrator
Ronnie was accused by someone of drink driving because of his movements, movements caused by his Parkinson’s symptoms, and the effects of his medication.

Ronnie
They took my licence off me, which was a big loss. A big [Inaudible]. They said I was drunk. Somebody reported me to the police.

Interviewer 1
Really?

Ronnie
They said I was drunk, drink driving. And they came to the door ten minutes after I got in. And they came in. They told me somebody had been in touch with them, they said I was drink driving. I don’t know who it was, but I’m not bothered. If they thought I was drink driving that was fair enough. They did the right thing. So I wasn’t even--

Interviewer 2
You weren’t drink driving though.

Ronnie
No I wasn’t. They breathalysed me and I passed completely. Nothing. [Inaudible]. And then I says, "what? I hadn’t done anything." But they did, and they took my license off me.

Interviewer 2
So that’s part of your independence.

Ronnie
It was a big loss, yeah.

Interviewer 2
A big big loss.

Ronnie
Even just toddling to the shops, I can’t do that. There’s times where I can’t really say, right, I’m going to the shops to get this, I can’t. And then the bus stops quite a way from here. Back on Union Road.
I think it says six minutes on Google Maps to the bus stop but to me it’s half an hour really. And I’m absolutely screaming by the time I get there, my legs are killing me.

[Music playing]

[Music playing]

Back to Session 8 MediaContent 2
Uncaptioned interactive content

Transcript

Jean Ballantine

Mel went into hospital. He had his surgery. It was fine. I got a phone call, and it was Mel. And he said, are you in that house? And I said, yes. Well, I’m in this ward. Then he hung up. And I went in to visit him that night, and he was just totally out of character. Nothing like Mel at all. Everybody that walked past the bed, he was shouting at them and waving. Nothing, nothing like him, was it? But you don’t remember that bit. And I went to the staff nurse in the evening, and I said, there’s something not quite right. There’s something different about Mel. Oh, Mel’s fine. He’s been getting his medication on time. There’s nothing wrong with him at all. Well, the next day, I went in, and what a shock. Mel was asking me to bring him earmuffs in. They’re hiding you in these cupboards, and they’re controlling me and telling me not to look for you. They’re playing music. It’s putting me off, this music, and I’m getting out of bed to look for you, because I know you’re here. So I phoned the next morning, 6:00 in the morning, spoke to the staff nurse. And asked how Mel was. And she said, Mel says he’s had a hell of a night, and he’s in tears, and he wants to know where you are. And we’re trying to tell him you’re not here, but he says you are. We are hiding you to prove to you that he’s too violent to live with. And he’s trying to climb out of bed, and we can’t keep him in, and he just had a hip replacement. Please come to the hospital to visit as soon as you like, and stay as long as you like.

So I did for five days. I left home at 10:00 in the morning, and I got home at 10:00 at night. And these five days, I kept saying to Mel, don’t worry. This is going to pass. This is going to pass.
You’ll be fine. You’ll be fine. I don’t think I believed it myself, to be honest.
And for five – torturous days, I really thought I’d lost Mel, that he’d gone. And then he said to me one day, they’re going to shoot me tomorrow. They’re coming here – to shoot me – because I’m too violent to live with you. So I won’t be coming home again.
So I went to the staff nurse, and I took Mel’s medication list with me, and I said there’s something so wrong. I don’t know what it is, but this is Mel’s medication list. Are you sure it’s right?
Oh, says she. I think the timings not quite right. The dosage is right, but the timings not quite right.
The next day, the phone rang, and a voice said, I’m back in the land of the living. And you just could not believe, what that was like. So that was a big lesson for us, how much difference one wee tablet can make.

Back to Session 12 MediaContent 1