

MY VOLUNTEER
INDUCTION

PARKINSON'S^{UK} CHANGE ATTITUDES. FIND A CURE. JOIN US.



CONTENTS

Welcome	4
Module one	7
What is Parkinson's?	7
Task one: About Parkinson's	9
Task two: True or false quiz	13
Top tips	15
Module two	17
How does Parkinson's UK support people?	17
Task one: Our vision and values	19
Task two: Our strategy	20
Task three: Volunteer clues	21
Task four: Sharing our achievements	25
Top tips	29
Module three	31
Volunteering practicalities	31
Task one: Things you need to know	33
Task two: Health and safety	39
Task three: Being an ambassador	41
Top tips	49
Module four	51
Managing your volunteering	51
Task one: Managing your time	53
Task two: Saying no	60
Task three: Exploring stepping back	64
Task four: Identifying when to take a step back	67
Top tips	72

WELCOME TO PARKINSON'S UK:

My volunteer induction

Whether you're helping out at a one-off event or making a longer-term commitment, welcome to Parkinson's UK – and thank you for volunteering with us.

This booklet contains everything you need to know about starting to volunteer with Parkinson's UK. From what Parkinson's is to how to manage your time, this is your volunteer induction.

“On behalf of the team of volunteers who put together this induction, we hope you enjoy it and your volunteering.”

Suzanne and Frank, Parkinson's UK volunteers

What is the volunteer induction?

Written by volunteers for volunteers, *My volunteer induction* has four main modules. These feature quizzes, activities and various scenarios to help support you in your volunteering.

- **Module one:**
What is Parkinson's?
- **Module two:**
How does Parkinson's UK support people?
- **Module three:**
Volunteering practicalities
- **Module four:**
Managing your volunteering

“Volunteers really are the lifeblood of Parkinson’s UK. On a daily basis I am inspired and motivated by the energy, commitment and drive of our volunteers.”

Steve Ford, Chief Executive, Parkinson’s UK

Why should I use the volunteer induction?

Whatever your volunteer role is, you’re helping to improve the lives of people living with Parkinson’s. You’re as vital to Parkinson’s UK as researchers and nurses. We hope this information helps you feel inspired, supported and informed.

The induction will help you understand:

- your role and how we will support you in it
- what we do and what Parkinson’s is
- why you are integral to our work to find a cure for Parkinson’s and improve life for people living with the condition
- policies like health and safety

How do I use the induction?

Talk to your staff contact to find out which parts to complete for your role. Send an email to **volunteering@parkinsons.org.uk** or call **020 7963 9328** if you’re not sure who your staff contact is.

It’s up to you which order you complete the modules in, and not all of them will be relevant to what you’re doing.

How do I find out more about volunteering roles for Parkinson’s UK?

Are you a social butterfly? You might like to help your local Parkinson’s UK group organise social events for people affected by the condition. Do you enjoy music? Sign up to be a steward at one of our fundraising concerts. There are all sorts of volunteering opportunities which support our work finding a cure for Parkinson’s and improving life for people living with it.

Visit parkinsons.org.uk or call 020 7963 9328 to find out more about volunteering roles near you.



MODULE ONE:

What is Parkinson's?

You might be affected by Parkinson's yourself and have some knowledge of the condition. Or you might not know much about it yet. Each person's experience of Parkinson's is different. As a volunteer, it's important that you understand how the condition affects someone so that you can talk about our work and/or best support people affected by Parkinson's.

“We hope you'll find the activities in this module interesting and helpful in preparing you to be a volunteer with Parkinson's UK and in working with people with Parkinson's.”

Dick, Volunteer

What you'll learn

At the end of this module, you can expect to be able to:

- explain that people with Parkinson's don't have enough of a chemical called dopamine because some of the nerve cells in their brain have died
- list the common symptoms of Parkinson's
- understand that everyone's experience of Parkinson's is different
- interact with people with Parkinson's appropriately
- provide our website address and helpline number for people who want to find out more about living with Parkinson's

Activities

This module consists of two tasks and some top tips:

- Task one: What is Parkinson's?
- Task two: True or false quiz
- Top tips

“I decided to volunteer for Parkinson’s UK as I wanted to work for an organisation that had a strong passion for helping people. I was interested in learning about Parkinson’s, a condition I knew very little about.”

Amilia, an administration volunteer





TASK ONE:

About Parkinson's

What causes Parkinson's? What are the symptoms and how does it affect someone's everyday life? For an overview of the key facts about the condition, please read the information below.

Defining Parkinson's

Parkinson's is a progressive neurological condition. It doesn't directly cause anyone to die, but symptoms worsen over time.

People with Parkinson's don't have enough of a chemical called dopamine because some of the nerve cells in their brain have died. Symptoms start to show when around three quarters of nerve cells in the brain are affected by the lack of dopamine.

There's no cure at the moment. But drugs, which need to be taken on time, and treatments can manage symptoms. Most people who are diagnosed are over the age of 50 but younger people can get it as well.

What are the symptoms?

Symptoms and how quickly they progress are different for everyone. Some of the most common symptoms are related to movement and include:

- tremor or shaking
- slower movement
- walking with small, shuffling steps
- stiffness or cramping muscles
- freezing
- lack of facial expression

Some people can experience symptoms not related to movement, including:

- depression
- tiredness
- pain
- skin, scalp and sweating problems
- hallucinations and delusions

What can you do to help?

Parkinson's can make people freeze to the spot without warning. It's best to not move someone in this situation as they could fall over. Ask if they need help – it usually takes a few minutes for someone to start moving again.

If you see someone having difficulty eating in a café or restaurant, please don't stare or make comments. It's upsetting and can make it harder for people with Parkinson's to go out in public.

What's living with Parkinson's like?



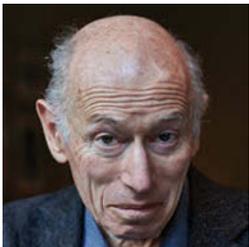
"You can freeze to the spot."

Terry



"You can lose the ability to communicate."

Ben



"When I'm anxious, Parkinson's affects me more than usual and I really don't feel in control."

Mark



"Your muscles can get so stiff, it's hard to even move."

Diane



"You can get very ill if you don't get your medication on time."

Phil

"Because of my volunteering, I not only know a little more about Parkinson's and research, but enjoy very rewarding involvement in the work of Parkinson's UK."

George, lay grant reviewer







TASK TWO: True or false quiz questions

Thinking about what you know about Parkinson's and what you've learnt from task one, decide whether each of the statements below are 'true' or 'false'. Turn over the page for the answers.

- 1** People with Parkinson's experience the same symptoms.
True / False
- 2** Every hour, someone in the UK is told they have Parkinson's.
True / False
- 3** People with Parkinson's may experience difficulty swallowing food or drink.
True / False
- 4** Parkinson's only affects the over 50s.
True / False
- 5** The main symptoms of Parkinson's are tremor, rigidity and slowness of movement.
True / False
- 6** There is no cure for Parkinson's.
True / False
- 7** Parkinson's is caused by a lack of the chemical dopamine in the brain.
True / False
- 8** Symptoms of Parkinson's appear when all the nerve cells in the brain have been affected by a lack of dopamine.
True / False
- 9** If a person with Parkinson's has 'frozen', you need to shout at them to get them to move.
True / False
- 10** To stop symptoms getting out of control, people with Parkinson's need medication on time every time.
True / False



TASK TWO: True or false quiz answers

Thank you for completing the quiz. Find out how you did below.

1 **False.** Everyone's experience of Parkinson's is different.

2 **True.** Because we're here, no one has to face Parkinson's alone.

3 **True.** Parkinson's can make the muscles in the jaw and face weaker, which affects chewing and swallowing.

4 **False.** Parkinson's is more common in the over 50s but younger people get it too.

5 **True.** Some people can experience symptoms not related to movement, such as pain and depression.

6 **True.** But, with your help, we're working hard to find one.

7 **True.** This is because some nerve cells in their brain have died.

8 **False.** Symptoms start to show when around 70% of nerve cells in the brain are affected.

9 **False.** It's best to offer someone help and be patient as it may take them a few moments to get moving again.

10 **True.** Medication for Parkinson's needs to be taken on time. This is one way that people with the condition can stay in control.

“The greatest reward is knowing that, as a result of something you've said, life will be easier for someone with Parkinson's.”

Bridget, who delivers education sessions in care homes

TOP TIPS

- 1** Make a note of our website parkinsons.org.uk and helpline number **0808 800 0303**, a confidential service providing support to anyone affected by Parkinson's. Use these to point people in the right direction if you're asked for advice or information about living with Parkinson's.
- 2** Ask your staff contact if you're not sure how to find out an answer to a question you or someone you're helping has about living with Parkinson's. They can suggest where to find out more.
- 3** Visit the "About Parkinson's" section of our website to find out more about how the condition affects someone's everyday life and what treatments and therapies exist to treat it.
- 4** Read three key Parkinson's UK booklets to find out more about Parkinson's:
 - *A quick introduction to Parkinson's* order code L001
 - *Easy read information about Parkinson's* order code B501
 - *Parkinson's and you booklet* order code B181 or order code B181AUD for the audio version

To order these, call **0845 121 2354**, send an email to resources@parkinsons.org.uk or visit parkinsons.org.uk.
- 5** Visit the Parkinson's UK website and search "Parkinson's Awareness Week 2014" to better understand how having Parkinson's affects someone's life. You'll find more about the stories of the people living with Parkinson's featured in task one.

"Through volunteering, I've learnt I can make a difference, that Parkinson's UK is there for us and that every person with the condition experiences different problems."

Kim, branch committee member



MODULE TWO:

How does Parkinson's UK support people?

Why did you choose to volunteer for Parkinson's UK? That's a question a number of people might ask you when you're volunteering. It's important you know about what we do and why, and how we plan to find a cure for Parkinson's. This will help you understand, and explain to others, how your role is vital to achieving our vision and how it improves life for people living with Parkinson's.

“As a volunteer, you may be asked by members of the public or people who have Parkinson's about the different ways that the charity can support people, so you need to know a little bit about it.”

Anne, Volunteer

What you'll learn

At the end of this module, you can expect to be able to:

- explain the vision and values of Parkinson's UK
- identify how our five year strategy reflects our vision and values
- understand ways that staff and volunteers are working together to achieve the charity's strategic goals
- explain how your role is supporting and/or improving life for people affected by Parkinson's
- describe some of Parkinson's UK's recent achievement

Activities

This module consists of four tasks and some top tips:

- Task 1: Our vision and values
- Task 2: Our strategy
- Task 3: What do our volunteers do?
- Task 4: Our achievements
- Top tips

“Our vision – to find a cure and improve life for everyone affected by Parkinson’s – is ambitious and volunteers are key to making it a reality.”

Bill, chair of our Bedford and District Branch





TASK ONE:

Our vision and values

Our values and vision guide our work. To achieve our ultimate ambition, we need to work together. As a new volunteer, we need your support to make our plans a reality.

Your task

Please read our vision and values below. Once you've read them, make a few bullet point notes about how your volunteer role contributes to our vision. If you're unsure, ask your named staff contact next time you speak to him/her.

You'll spot more examples of our values in action throughout this induction and in your volunteering work with Parkinson's UK.

Our vision

The hopes and views of people affected by Parkinson's helped us identify our clear vision for the future **to find a cure and improve life for everyone affected by Parkinson's.**

Our values

We listen. Everything we do is based on the experiences of people affected by Parkinson's.

We unite. We bring everyone together behind one shared vision.

We inspire. Our passion and determination inspire those around us.

We innovate. We are forward thinking, always seeking to improve.

We're inclusive. We reach out to the whole Parkinson's community.

We focus. We deliver results and make the most of our resources.

“Parkinson's UK is very well organised and provides a vital service. The more you are occupied, the less you think about your own Parkinson's.”

Colin, lay grant reviewer



TASK TWO: Our strategy

Parkinson's UK has big plans and, as a volunteer, you're a key part of them.

Your task

Read our strategy document. It's about what we want to achieve in the next five years. Can you see how our values and vision have helped us decide what our next priorities are?

Our 2015–2019 strategy sets out the steps Parkinson's UK, and those with an interest in the condition, can take to transform people's lives. It's based on the views of people with Parkinson's, families and carers. They told us what would make the biggest difference to their lives, and three key things stood out, which the strategy focuses on:

- Finding a cure and developing better treatments
- Making sure the right services are available everywhere
- Empowering people with Parkinson's to take control

“I started volunteering for Parkinson's UK in the mid 1980s when my late husband was diagnosed. The organisation has evolved and become very user-friendly. Staff are supportive and keep me on the right track when I organise things.”

Sylvia, local branch volunteer



TASK THREE:

Volunteers clues

From taking photos at events to reviewing research funding applications, our volunteers do all sorts of things to improve the lives of people with Parkinson's.

Your task

Can you guess the volunteer role from the pictures below? Turn to page 24 to find out if you are right

A





TASK THREE:

Volunteer clues – continued

B



C



D



E



F





TASK THREE: Volunteer clues – answers

How many volunteer roles did you identify? Find out below.

A **Volunteer educators** talk about Parkinson's to staff in nursing and care homes.

B **Event volunteers** help with everything from marathons to concerts. They might be marshals, run the registration desk or hand out water to participants.

C **Telephone peer support volunteers** talk to people with Parkinson's and carers on the phone who have a similar experience of the condition.

D **Regional fundraising volunteers** raise money for Parkinson's UK in their local area. They might organise a collection or talk at a Rotary Group.

E **Research Support Network volunteers** review grant applications for research into Parkinson's. They also organise events so more people can learn about research into the condition, and some have even represented Parkinson's UK at international conferences.

F **Our local network of branches and groups** provide people affected by Parkinson's with friendship, support and the opportunity to meet others in similar situations. Some also offer singing, exercise classes, outings and other therapeutic and social activities.

Were you surprised at the different ways volunteers support people affected by Parkinson's? This list isn't exhaustive, we've just chosen a few examples and volunteer roles change all the time. By volunteering for Parkinson's UK, you're improving lives. Thank you!

“My advice to new volunteers is to find out what's involved in the role you're volunteering for. Do you have the time and energy to do justice to the role? It helps if you have had previous experience of similar tasks.”

Aneurin, branch fundraiser



TASK FOUR: Sharing our achievements

Volunteers founded Parkinson's UK in 1969. For more than 40 years, staff and volunteers at the charity have worked together, united by a passion to find a cure and improve life for everyone affected by Parkinson's. You're joining a charity that has achieved so much.

Your task

It's so important that you understand what Parkinson's UK does and what the charity has achieved. Then you can talk knowledgeably about our work to people you meet as a volunteer. Read the 10 achievements on the next page.

Think about which of the 10 you could mention if the following people asked you about Parkinson's UK's achievements (suggested responses are on page 28):

- 1** Someone with Parkinson's interested in the charity's work.
- 2** A potential new volunteer interested in how they can make a difference to the lives of people with Parkinson's.
- 3** Someone you meet volunteering at an event who is interested in donating to the charity.
- 4** Someone from the local pub who's interested in selecting Parkinson's UK as the recipient of their monthly charity quiz.





TASK FOUR: 10 achievements

- 1** Parkinson's UK is the largest charity **funder of Parkinson's research** in the UK. So far, we've invested almost £70 million in groundbreaking research, money which our volunteers helped us raise.
- 2** We have more than **370 volunteer-run local groups** across the UK, offering friendship and support to everyone affected by Parkinson's.
- 3** In 2014, there were more than 2 million visits to **our website and our Facebook and Twitter** audience grew by 60%. That means more people affected by Parkinson's are getting access to vital information, including volunteers.
- 4** People have viewed our **Parkinson's Awareness Week 2014** video about what life is like with the condition more than 60,000 times. Volunteer actors, script reviewers and camera operators helped make the film, which was shortlisted for a charity sector award.
- 5** Thanks to our staff and volunteer **campaigning**, there are now more than 350 Parkinson's nurses across the UK, supporting people with the condition to stay independent.

“I volunteer because I have Parkinson’s and it’s important for me to help others. It’s also a good way of networking and gives me tips on how to manage my condition.”

Helen, self-management facilitator

6

In 2013, we launched our **self-management programme** to train volunteers affected by Parkinson’s to support others in their community to find practical ways to manage life with the condition.

9

More than 6,000 people use our **online forum** for friendship and support. This includes those who have Parkinson’s, their carers, friends and family members, and volunteers.

7

Our professional **helpline** advisers and **volunteer telephone peer supporters** answer around 30,000 calls a year to people affected by Parkinson’s. Advisers provide information and advice, and volunteers support peers living with the condition.

10

Through our **Research Support Network**, volunteers review grant applications for research into Parkinson’s. In 2014, research that we helped to fund found six new sections of DNA that increase someone’s chances of having the condition. This could lead to **new ways to prevent and treat Parkinson’s**.

8

Researchers can develop better treatments and make progress towards a cure using brain tissue provided by our **Parkinson’s UK Brain Bank**, the largest dedicated to Parkinson’s in the UK. Volunteer fundraising helps make this possible.

*Please note general figures stated above are from January 2015.



TASK FOUR: Our achievements – answers

There are no wrong or right answers but here are our suggestions.

1 For someone with Parkinson's interested in the charity's work, you could mention achievement number seven.

2 For a potential new volunteer interested in how they can make a difference to the lives of people with Parkinson's, you could mention achievement number two.

3 For someone you meet volunteering at an event who is interested in donating to the charity, you could mention achievement number one.

4 For someone from the local pub who's interested in selecting Parkinson's UK as the recipient of their monthly charity quiz, you could mention achievement numbers one and seven. You could also thank them for considering Parkinson's UK and say that the charity's work relies on voluntary donations.



TOP TIPS

- 1** Read our impact report for more information about what Parkinson's UK is doing and the people you are supporting. To receive your free copy, call **0845 121 2354**, send an email to **resources@parkinsons.org.uk** or visit our website **parkinsons.org.uk/publications**
- 2** Become a member of Parkinson's UK for £4 a year to receive our membership magazine *The Parkinson* which has all the latest news about what the charity is doing. To sign up, call **020 7932 134** or send an email to **join@parkinsons.org.uk**
- 3** Join the mailing list for our free twice yearly magazine *Progress* about the latest research into Parkinson's. Sign up using the above contact details.
- 4** If you or someone in your family has access to the internet, you can 'like' us on Facebook or 'follow' us on Twitter to keep up to date with the latest news from Parkinson's UK. You can also watch our videos on YouTube and find photos from our events on Flickr.

“My advice for new volunteers is: ‘get stuck in’.
Help in whatever way you can and be positive.”

David, branch vice chair



GO FORT!

0808 02 03
participating

Helping You
Healthy

RISKISMS CHANGE ATTITUDES FIND A CURE JOIN US

MODULE THREE:

Volunteering practicalities

You've joined a team of committed volunteers and staff who work together to find a cure for Parkinson's and improve the lives of those living with the condition. So, while you may be new to the organisation and are finding your feet, you're not alone. Parkinson's UK welcomes, encourages and values volunteers. We do our best to provide everything you need to know to carry out your volunteering role, from understanding health and safety issues to explaining how you claim expenses.

“Even if you've been a volunteer for years it's still important to do this module. This information is here for you in one place, and you can always come back to it if you need to.”

Elisabeth, Volunteer

What you'll learn

At the end of this module, you can expect to be able to:

- know what resources can support you in your role and explain why they're important
- have an awareness of health and safety issues affecting your volunteering
- identify and explain why some behaviour and decisions can be detrimental to Parkinson's UK

Activities

This module consists of three tasks and some top tips:

- Task one: Things you need to know
- Task two: Health and safety
- Task three: Being an ambassador
- Top tips

“As a volunteer, you will be amazed at the courage and determination and sense of humour of those who have Parkinson’s in what can be very difficult circumstances.”

Pat, branch secretary





TASK ONE:

Things you need to know

By now, you probably have a good idea of what Parkinson's UK does and who the organisation supports. If you'd like to find out more, please take a look at modules one and two.

Your task

Read about everything from claiming expenses to our policies on equality below. Some of the issues won't apply to what you're doing now but it's useful to know that these policies and resources exist should you need them in the future.

Equality and diversity

At Parkinson's UK, we're committed to promoting equality and valuing diversity in our work and organisational culture, including volunteering. We welcome volunteers from diverse backgrounds and work to ensure equal opportunities for all.

As a volunteer, you're also responsible for creating this culture of inclusion at Parkinson's UK. So, signing up to become a volunteer means carrying out your volunteering in a way that reflects the organisation's approach to equality and diversity.

Read more about this issue in our Equal opportunities and diversity policy.

Data protection

Under the Data Protection Act 1998, Parkinson's UK has legal obligations whenever it handles personal data. This is information that identifies a living person which is held on a computer (such as in electronic files, emails, or databases) or an organised filing system (including paper files in a filing cabinet or an archive box).

Personal data could include someone's name, address, email address, telephone number and date of birth. Under the Act, we need to make sure the information we keep about people is good quality, relevant, up to date, protected and secure.

Particular care must also be taken when handling sensitive personal data as more restrictive requirements apply to this type of information. This includes details of someone's racial or ethnic origin, political opinions or religious belief and sexual orientation, amongst others.

People have a right to request any personal data we hold about them and can do so by contacting our data protection officer.

If your volunteer role involves handling personal information, you must sign a confidentiality pledge.

It is important to report any data protection related incidents to your staff contact as soon as possible so that any adverse effects can be minimised. Do speak to them if you have any questions or concerns about this issue.

Read our Data protection policy (to be launched by summer 2015)

Confidentiality

The charity also owes a legal duty of confidentiality to the people we hold information about. That means restricting access to information to those who “need to know”.

Parkinson’s UK does not sell personal data, and in general does not share it with third parties unless it is legally obligated to or has someone’s consent.

Confidentiality is also an essential principle of the services we provide. So, to ensure that the people and organisations we work with trust us, it is vital that you understand what information we can and cannot share.

As a volunteer, someone might share personal information with you in the course of your role. For example, a carer could discuss their finances.

You must be careful not to share this information with others who don’t have a strict need to know as it can easily become gossip. Confidentiality is still important even if a situation might seem informal.

Your staff contact can help with anything that you’re concerned about around this issue and other formal support is available to volunteers in certain roles.

If your volunteer role involves handling confidential information, you must sign a confidentiality pledge.

Do report confidentiality-related incidents to your staff contact as soon as possible so that any adverse effects can be minimised. Do speak to them if you have any questions or concerns about this issue.

Read our Confidentiality policy (to be launched by summer 2015).

Safeguarding

We take people's safety very seriously at Parkinson's UK. That means everyone who works or volunteers for, or represents the charity, needs to show care and integrity to the people we connect with.

Safeguarding is about keeping vulnerable people safe, especially adults at risk of abuse, while protecting and supporting those who work and volunteer for us. It is important that you are aware of what to look out for and do if you're concerned about someone you meet through your volunteering.

Please read our Safeguarding booklet for England and, Northern Ireland, Scotland and Wales for more information about what to do if you become aware of a safeguarding issue.

Talk to your staff contact about who to call in your area if you have a safeguarding concern. If you are unable to reach them, or you are not a volunteer or group member and have any safeguarding concerns, please contact the designated protection officer on safeguarding@parkinsons.org.uk or call 0844 225 9853.

Claiming volunteer expenses

We don't want your volunteering for Parkinson's UK to disadvantage you in any way, including financially. So we'll reimburse all reasonable expenses that you incur when you carry out your volunteering activities for Parkinson's UK, according to our Volunteer expenses policy.

Ask your staff contact for a volunteer expense claim form and submit your receipts with it.

Further information can be found in the Volunteer expenses FAQ, and our Volunteer expenses policy.

Volunteering and benefits

If you are claiming state benefits, inform Jobcentre Plus about your volunteering. We can provide a letter confirming you are a volunteer if you need it.

In most cases, state benefits should not be affected if you are a volunteer. If you're claiming state benefits, you're allowed to receive expenses as long as they only cover out of pocket costs. If there's any kind of profit, your benefits could be reduced or suspended.

Speak to your staff contact if you would like to know more.

Induction, learning and development

This online induction aims to make you feel welcome, comfortable and supported in your role. You have the opportunity to ask your staff contact any questions about volunteering at Parkinson's UK.

We will provide opportunities for you to learn, such as training and networking events. These will help you perform your volunteering role effectively and give you an opportunity to expand your role if you want to.

Speak to your staff contact to find out more.

What support you can expect from Parkinson's UK

We appreciate and recognise all volunteering contributions, no matter how big or small, in ways that are meaningful, from sending thank you cards to featuring case studies in our communications.

Your staff contact is there to support you. Do discuss any issues and concerns that you may have with them, as well as your progress, any successes, and your learning and development needs.

Speak to your staff contact to find out more.

If you have any problems

We hope that you won't experience any problems while you're volunteering, but know that, sometimes, issues can arise. For example, perhaps you're experiencing a problem involving another volunteer or are struggling to carry out your role.

Our problem solving policy and procedure provides a framework for how we try to solve problems involving volunteers in an open, fair and timely manner.

Speak to your staff contact to find out more about how we can support you to resolve any problems you're having in your volunteering role.

Read our problem-solving policy and procedure.

Giving feedback and making a complaint

We want to hear all your feedback, whether it's positive or negative.

So, if you have a complaint, comment or compliment about anything to do with Parkinson's UK, do let us know.

You can send an email to feedback@parkinsons.org.uk, call us on 020 7963 9324 or write to us at User involvement manager, Parkinson's UK, 215 Vauxhall Road, London SW1V 1EJ.

Moving on

We hope you enjoy being a volunteer for Parkinson's UK. However, we know that sometimes people want to move on from their volunteer role, for a wide variety of reasons.

If you want to do this, please inform your staff contact, giving as much notice as you can. You will be asked to complete a moving on questionnaire to help us to learn from your experience.

There may be times when Parkinson's UK will need to end a volunteer role because of changes in circumstance, funding or organisational structure. If this happens, you'll have as much notice as possible. You will also have the opportunity to discuss how you feel with your staff contact, and where possible and appropriate, will be offered an alternative volunteer role.

Complete module four to help you think about times when it might be appropriate to move on from your volunteering.

“Everyone has something to offer as a volunteer, even if it's just to raise the profile of Parkinson's, getting people talking about and being more aware of the condition”

Marjorie, branch treasurer



PARKINSON'S^{UK}
CHANGE ATTITUDES
FIND A CURE.
JOIN US.

W. CA
EAT



TASK TWO: Health and safety

We want you to feel safe and secure in your volunteering role and have a moral and legal duty to ensure you do.

Our health and safety procedures and policies cover everything from things to bear in mind when you're organising an event to staying safe on the roads. They outline how we'd like volunteers and staff to work together to minimise risk or injury.

Your task

Talk to your staff contact about which of the following issues are relevant to your role and they can print out the policies, and trainings that might be helpful.

Introduction to health and safety

It's vital you read our general introduction to health and safety at Parkinson's UK. This training will take around 20 minutes to complete and will help you think about what general health and safety issues apply to your volunteering role.

Driving safely

Whether you've had your license for 50 years or five, we'd really appreciate it if you could read this information on staying safe when you're driving on Parkinson's UK business. It will help to remind you of common driving hazards.

Assessing risk when you're planning an event

What's a risk and what kind of health and safety issues do you need to bear in mind when you're organising an event for Parkinson's UK? This training will take around 20 minutes to complete and will help you form a checklist of things to consider.

Sitting at a desk correctly and safe manual handling

You can cause damage to your body if you don't sit at a computer correctly and if you lift a heavy object in the wrong way. This training addresses both these issues and will help you minimise the risk of injury. It will take around 30 minutes to complete.

Health and safety in the office

It's important to think about any hazards when you're volunteering in an office environment, from too many plugs in a socket to overstocked cupboards. This training highlights things to look out for and should take around 35 minutes to complete.

Personal safety

From things to think about if you're on your own to what to do if you're worried about someone's behaviour, this training will help you take responsibility for your safety whilst volunteering.



VOLUNTEER

PARKINSON'S™ CHANGE ATTITUDES. FIND A CURE. JOIN US.

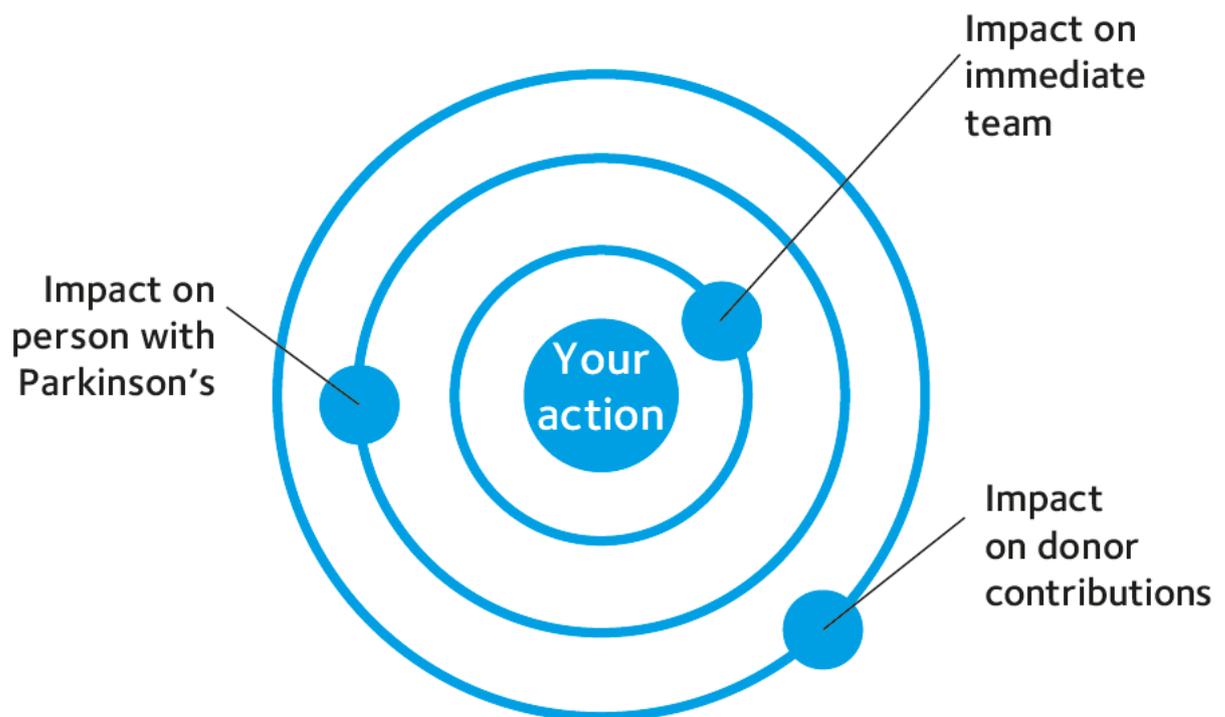


TASK THREE: Being an ambassador

“We” at Parkinson’s UK, includes staff and volunteers, working together. We’re all working to find a cure for Parkinson’s and to improve life for everyone living with the condition. Our common values are at the heart of everything we do, and form the basis of how we work together to achieve our aims.

Your task

As a new volunteer, it’s important that you familiarise yourself with the values and bear them in mind when you’re representing Parkinson’s UK. If you haven’t already, you can familiarise yourself with our values in module two, task one.



Why do we ask you to do this?

Because even your smallest decision or action as a volunteer can have a wider impact on the charity.

You might be familiar with the ‘ripple effect’, and above, you can see how the concept can be applied to your volunteering.

Maria's story

Maria and her local Parkinson's UK group are planning an event to help pay for a new exercise class. Group members have five minutes to put forward their ideas. Maria can't wait to tell everyone about the great venue she has found for the event. As Alwyn and Steve, who are also volunteers, begin to share their thoughts, Maria starts to interrupt and say why her idea is so much better.





Maria remembers the charity's values

1

Maria **remembers the charity's values** and realises that she is acting selfishly. She immediately apologises to the group for interrupting.

2

She makes an effort to listen to everyone's suggestions, shares her own and gives constructive feedback. A unanimous decision is made on the venue for the event.

3

All the volunteers from the group turn up at the event and work together to get as many people as possible to donate to Parkinson's UK.

4

At the end of the event, Josh, another volunteer, is delighted to tell the staff contact that the group have raised enough money to start running the exercise class for people with Parkinson's. He thinks the group's teamwork was key.



Maria forgets the charity's values

1

Maria has **forgotten our values** about listening and being united.

2

Alwyn, Steve and the rest of the group feel awkward and tense because Maria has been rude. A venue is decided upon quickly.

3

Alwyn and Steve decide to not attend the event because they were upset by how Maria behaved in the initial meeting.

4

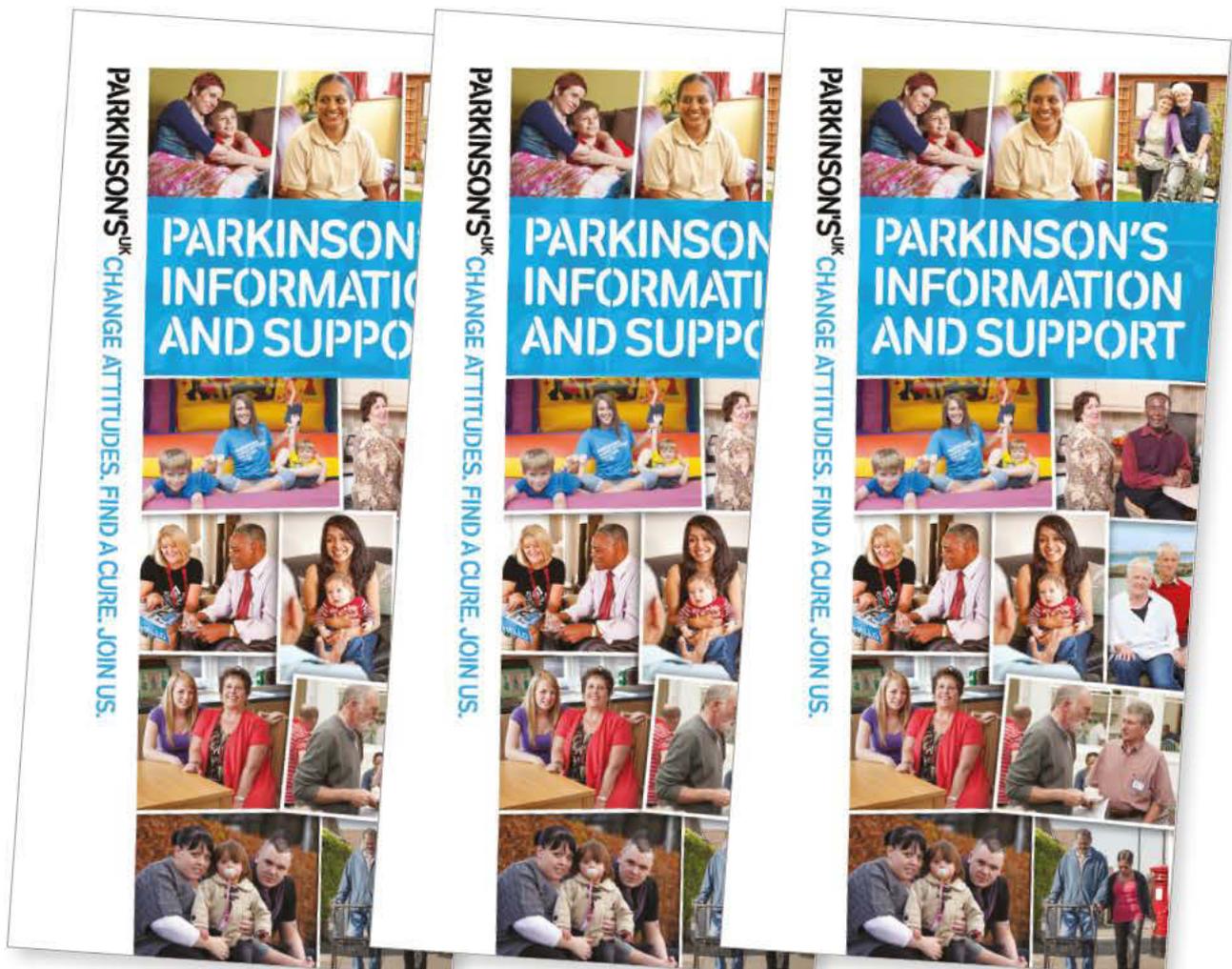
Alwyn and Steve leave the group because they'd expected Maria to apologise and felt her actions had caused too much bad feeling. The event doesn't happen and Josh, another volunteer, is disappointed to tell the staff contact that the group can't run the exercise classes for people with Parkinson's.

Ultimately, the way we all work together has an impact on the people at the heart of our charity – those living with Parkinson's. Your friendliness and kindness makes a difference.

James's story

Minda has been organising a volunteer group to distribute Parkinson's UK leaflets at local surgeries and pharmacies. James is one of the people who will deliver the leaflets. He thinks it would be helpful to take half to a cycling shop as he knows the owner. Minda, and the rest of the group, aren't sure this is the best thing to do with the leaflets as they have lots of places to target.

The group asks James to only take a handful of leaflets to the cycling shop. James tells the group he is unhappy with their decision and gets angry.





James remembers the charity's values

1

When James gets home that evening, he decides to ring his staff contact, Dennie, at Parkinson's UK. They discuss his issues and Dennie **reminds him of Parkinson's UK's values.**

2

He sees how it will benefit the group if he acts more cooperatively in future.

3

Iman is thinking of making a monthly contribution to Parkinson's UK and visits our Facebook page to find out more about our work. She reads a positive post from a volunteer working within the charity. Iman decides to donate £11 a month to Parkinson's UK.

4

Over two years, Iman's contribution funds a whole day of research, helping bring us one step closer to finding a cure for Parkinson's.



James forgets the charity's values

1

James has **forgotten our values** about being innovative, united, listening and focusing.

2

When he gets home that evening he posts a negative comment about the group under a comment about volunteering on the Parkinson's UK Facebook page.

3

Iman is thinking of making a monthly contribution to Parkinson's UK and visits our Facebook page to find out more about our work. She sees James' comment at the top of the page and is concerned that her money may not be used wisely. Iman decides to donate to another charity.

4

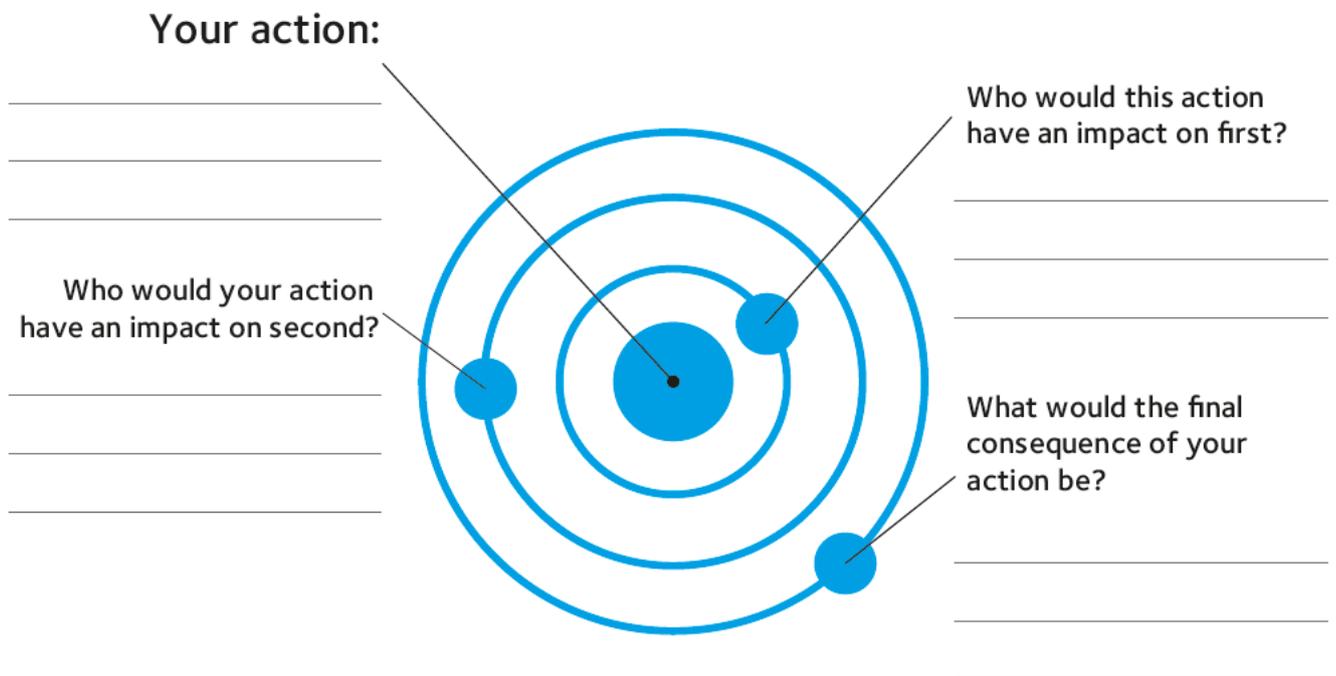
Over two years, Iman's contribution (£250) could have funded a whole day of research into a cure and better treatments for Parkinson's.

Ultimately, the way we all work together has an impact on the people at the heart of our charity – those living with Parkinson's. Your friendliness and kindness makes a difference.

“I’ve learnt that Parkinson’s UK has many very dedicated, knowledgeable and experienced staff. I’d advise new volunteers to learn as much about the condition as you can”

Dick, who helps interview new staff at Parkinson’s UK

Now try filling out your own version of the ripple effect diagram.





TOP TIPS

- 1** Revisit the information in this module if you need to at a later date. Some of it might not apply to your volunteering at the moment but could be useful in the future.
- 2** Speak to your staff contact if you have any questions about Parkinson's UK policies and procedures that can support you in your volunteer role. You'll find these in tasks one and two.
- 3** Look out for case studies of volunteers who are great ambassadors for the charity in your regional Parkinson's UK publications.

“Volunteering for Parkinson's UK has given me a new lease of life and helped me make some good friends. I get so much more out of it and so will you.”

Jenni, who gives talks on living with Parkinson's



PARKINSON'S^{UK}
CHANGE ATTITUDES.
FIND A FRIEND
JOIN

MODULE FOUR:

Managing your volunteering

Time is precious and we are hugely grateful that you are volunteering some of yours to support people living with Parkinson's. We also know that managing your volunteering with everything else in your life can be challenging. Existing volunteers told us that this induction needs to include tasks around managing your time and when doing less volunteering might be appropriate to help you take a step back if you need to. Do talk to your staff contact about which tasks to complete in this module.

“Parkinson's UK really values volunteers and the contribution you make, but we don't want to wear you out or take all of your free time. This module helps you find out more about managing your time as a volunteer.”

Frank, Volunteer

What you'll learn

At the end of this module, you can expect to be able to:

- understand some of the ways volunteers manage their time
- explain some of the reasons why it might be appropriate for someone to step back from their volunteer role

Activities

This module consists of four tasks and some top tips:

- Task one: Managing your time
- Task two: Saying “no”
- Task three: Deciding when to take a step back
- Task four: Identifying when to take a step back
- Top tips

“Be honest with yourself about what you are able to do. I fit my volunteering around my work commitments. I’m able to do a lot online ad hoc as opportunities are sent to me, or I keep tabs on the research involvement opportunities.”

Anne Ferrett, Research Support Network volunteer





TASK ONE:

Managing your time

Some volunteering activities are easy to organise, while others are more involved. But even simple volunteering tasks need a little planning.

You might have experience of planning and developed time management skills from paid work or other areas of your life, which will support you in your volunteering role. Or, perhaps you're looking to get more experience of these things.

Whatever your skills in this area, it's important that you think about how much time you can give and what planning your volunteering role might need. Then you will feel more comfortable with your volunteering commitments.

Your task

Take a look at the two situations on the next few pages and think about how you would plan your time. They are based on real situations using a combination of scenarios.



Trisha's collection tin day

Trisha has agreed to stand with a collection tin at a local event to raise money for Parkinson's UK.

What practical things will she need to think about to make sure she is prepared for this task? Once you've noted down your ideas, turn the page to read ours.

Now you've created a list for Trisha, think about what might be on your own if you were volunteering at the event. Not sure? You could always talk to the collection tin co-ordinator or share the task with other volunteers.



Managing your time answers

There are no wrong or right answers, but here are some of our ideas. Trisha could consider the following to prepare for her collection tin day:

- Is she available on the day of the event?
- How much time (and energy) can she give?
- How will she get there?
- Can she get to the event on time?
- What will she need to wear and take with her?
For example, an umbrella, coat or sunscreen.
- When and where will she meet the collection tin co-ordinator?
- What does she need to do with the tin at the end of the day?



PARKINSON'S^{UK}
CHANGE ATTITUDES.
FIND A CURE.
JOIN US.

PARKINSON'S^{UK}
CHANGE ATTITUDES.
FIND A CURE.
JOIN US.

PARKINSON'S^{UK}
CHANGE ATTITUDE
FIND A CURE.
JOIN US.

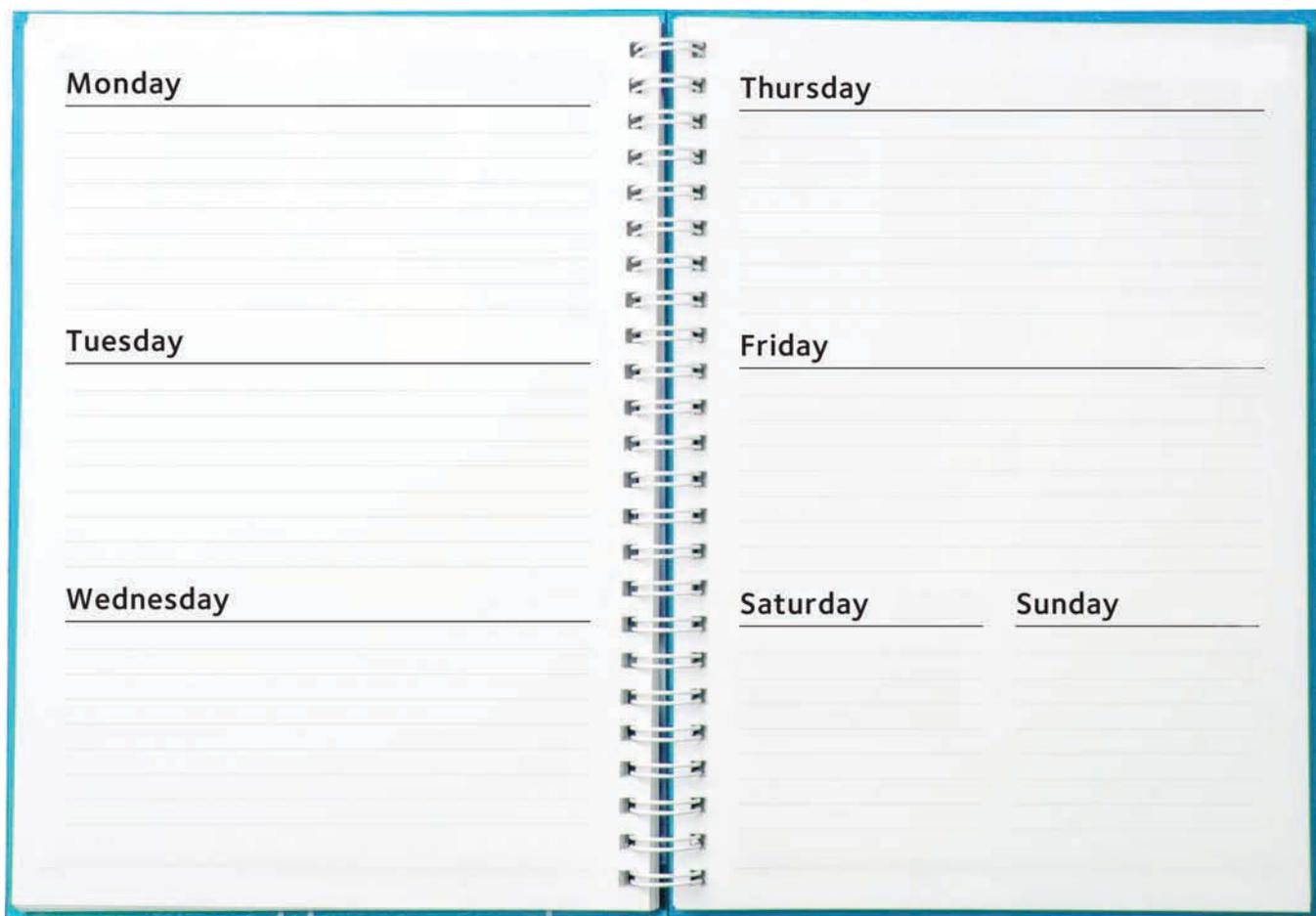
25
SINCE 1949

155
SINCE 1949

Nav's leaflet drop

Nav volunteered to take leaflets about living with Parkinson's to local GP surgeries to raise awareness of the condition and Parkinson's UK. Steve, his staff contact, asks Nav if he could visit three surgeries by Friday as they nearly have none left. Jan, from his local group, is also helping.

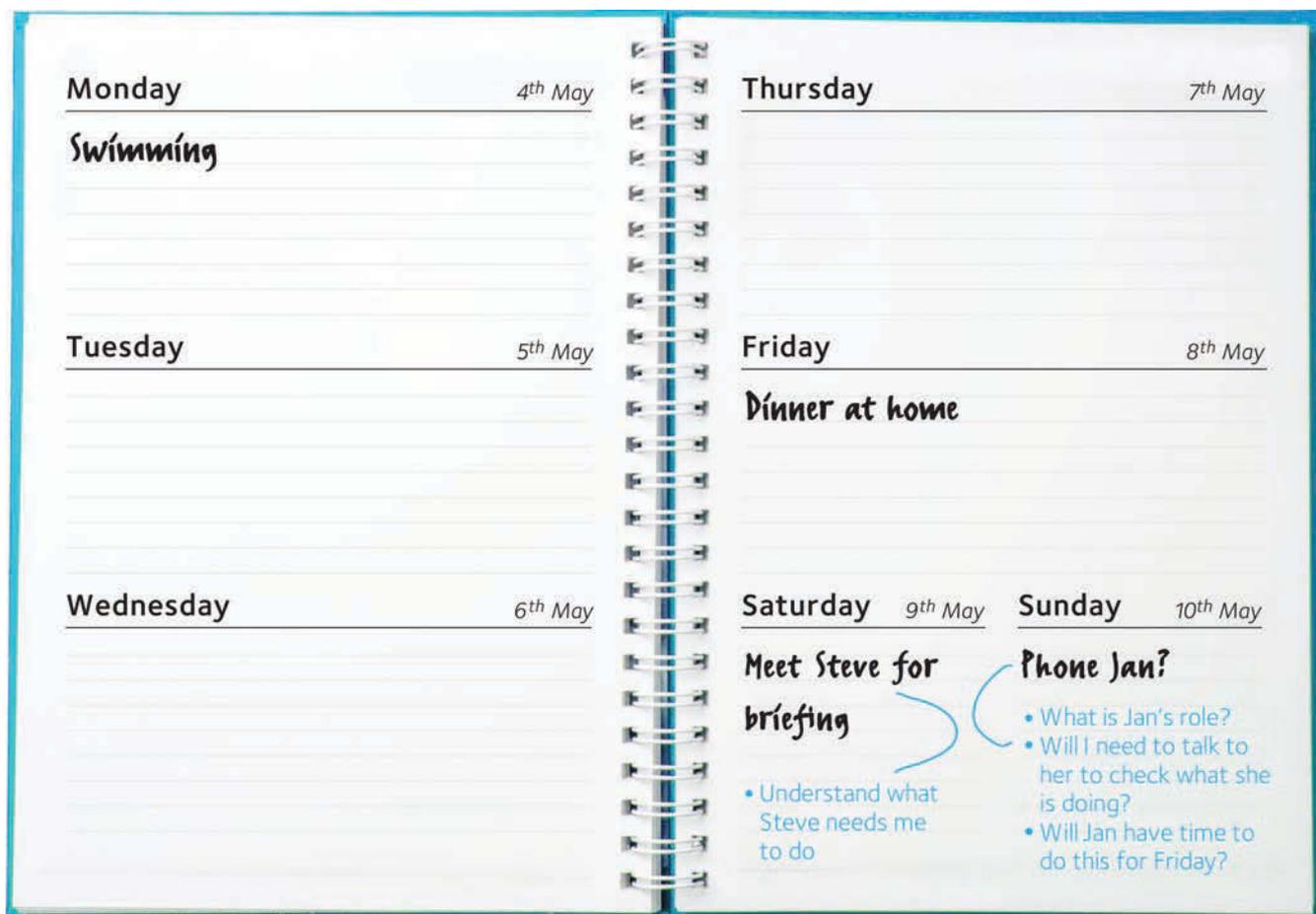
Below is a blank page from Nav's diary. What would he need to do to plan the leaflet drop for Friday?



When you've jotted down some thoughts, see the next page for Nav's ideas.

Here are some pages from Nav's diary showing his thoughts about planning the event.

Week one



“I have spent a great deal of time researching the illness and it makes me realise how big the mountain is that we have to climb to find a solution. It's important that we do our bit to ensure that a cure is found for future generations.”

Michael, volunteer educator

Week two



Did you think of any ideas that Nav didn't include? Remember that practical considerations vary from person to person and you can talk to your staff contact if you're worried or not sure about any aspect of your volunteering.



TASK TWO: Saying no

Sometimes you won't be able to volunteer, even if you have in the past.

That might be because you:

- don't have the time
- are busy or not available
- don't have the energy
- need a change
- have health considerations

It does not matter why you can't volunteer at these times, and you don't need to explain if you don't want to. It's important that you don't feel bad in any way if you can't or no longer want to volunteer.

We want you to volunteer for Parkinson's UK for as long as you're able and want to, of course. But it's always ok to say "no" and be proud of how you have volunteered in the past.

Your task

Kerrie is part of a local support group and is a volunteer support group helper. She has a quandary. Read this on page 62 to consider how you might approach saying "no" to taking on volunteering tasks.

"My advice to new volunteers is to get involved! You will get a lot of satisfaction from your input, but don't overdo it."

David, Reading branch chair



Kerrie's quandary

Kerrie is part of a local support group and is a volunteer support group helper. She has a quandary. What would you do if you were her?

Leon, the support group co-ordinator, asks Kerrie if she can give any extra time. Kerrie does not feel she can take on any more. Which of the following is not an appropriate way to explain her decision to Leon?

- A** Telling him she can't take on any more volunteering at the moment.
- B** Saying "Sorry, no, I can't" but not explaining why.
- C** Saying "yes" but calling Leon when she gets home to explain she has changed her mind.

See page 63 to find out.

Saying 'no' answer

- ✔ **A** Telling him she can't take on any more volunteering at the moment.
- ✔ **B** Saying "Sorry, no, I can't" but not explaining why.
- ✔ **C** Saying "Yes" but calling Leon when she gets home to explain she has changed her mind.

Kerrie's quandary

All the answers are correct! Of course it would help co-ordinators to have as

much notice as possible but it's always ok to say "no" if you can't take on a volunteering task.





TASK THREE: Exploring stepping back

Circumstances change and sometimes you might need to think about taking on less volunteering. But as a committed, passionate and enthusiastic volunteer, this can be a tricky decision to make. Yet it is possible to over-extend yourself and experience burnout.

Your task

Read our three fictional examples which are based on the type of difficulties volunteers have encountered in the past.

1

Too much on my plate

"I've been volunteering for Parkinson's UK since 2004. I run a support group, sit on the committee for my local group and am on the steering group for Parkinson's nurses. It's almost the same as having a full time job.

"I have Parkinson's myself and take great joy from helping others. Last year, I found there were days when my condition made it hard for me to cope and I was worried that I would not be able to do all of my volunteer roles. I soon realised that the time had come for me to lighten my load and make some difficult choices.

"I had to learn to start saying: 'Sorry, but I will no longer be available to do that'. With a reduced workload, I can now focus my efforts on the things I enjoy the most.

"If you are already starting to spread yourself too thin, don't feel obliged to take on more. Volunteer overload is not good for you or Parkinson's UK."

2 **Volunteering is not a good idea at the moment**

“There are certain times in your life when your volunteer activities will need to wind down and take a backseat to your own life.

“I am the programme secretary for my local group of Parkinson’s UK. Following a serious car accident, my partner was hospitalised for several weeks.

“With lots of visits to the hospital and the prospect of caring for him at home for some months, I became very worried that I would not be able to complete my volunteering role.

“I asked my local branch if I could step down temporarily and they appointed an assistant programme secretary to take on the workload.

“Four months later, I am pleased to say that my partner is well enough for me to return to my volunteer role. And now I have a valuable assistant to share the workload.”

“By volunteering for Parkinson’s UK, I’ve learnt to be patient with others and to adjust my capabilities as my Parkinson’s medications take or lose their effect.”

Geoff, volunteer policy reviewer

3

I can't commit to a regular volunteering role anymore

"Over the years, I have become much more involved with Parkinson's UK than I ever could have imagined. I am proud to have played a role in running my local group and I am a lay grant reviewer. I particularly enjoyed being able to take a very hands on approach when it came to organising local fundraising events.

"My partner has Parkinson's and his condition has advanced so I've found it more difficult to find the time to volunteer recently. However, I am determined to still do anything I can to provide friendship to other people affected by Parkinson's.

"I've joined the online forum on the Parkinson's UK website. It has given me a whole new lease of life and a network of friends that I communicate regularly with, without leaving the house.

"If you'd like to support people affected by Parkinson's but are unable to commit to a regular volunteering role, there are lots of other ways to help."



TASK FOUR: Identifying when to take a step back

Many things can happen that make volunteering challenging. We don't want to discourage you from volunteering for Parkinson's UK. But it can be good to identify times when you might have very good reasons for taking a step back from your volunteering.

Your task

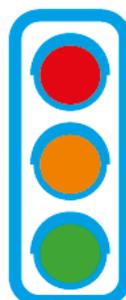
The fictional examples on the next two pages are based on problems our volunteers have told us about. Please can you:

- 1 Read Emily and Fred's challenges and pause when you're asked to.
- 2 Think about what they should do and why.
- 3 Then select the appropriate traffic light to decide what you think Emily or Fred should do.

What can Emily do?

Select:

- Red to indicate that Emily/Fred need to stop volunteering within this role.
- Amber if Emily/Fred may be able to continue if some changes are made.
- Green if you think there's no problem.



STOP!

What needs to change?

Caution!

What might help in this situation?

Go ahead!

There is no real problem.

Challenge one

Emily has volunteered at Parkinson's UK events for five years. She really enjoys working as part of the team. She has Parkinson's and is determined to keep as active as possible. But she is finding that standing all day at events is very tiring. By the end of the day she is too tired to drive home. On the way home, Emily sensibly stops off at a service station for a break from driving.

PAUSE.

Is it best for Emily to step back from her volunteer role? Is this a red, amber or green situation? See page 69 to find out what happened next.

Challenge two

The following year, the event coordinator notices that Emily is really struggling in the afternoon and that her Parkinson's symptoms are causing her some difficulty. They have a cup of tea and a chat. Emily is exhausted and upset at the thought of stepping back from volunteering. The event coordinator is worried about Emily and thinks she is overdoing it, and is also aware that the rest of the team are having to work extra hard to support her.

PAUSE.

Is it best for Emily to step back from her volunteer role? Is this a red, amber or green situation? See page 69 to find out what happened next.

Challenge three

Emily is moving home to live nearer to her family. This means she has to drive a long way to the events that she is involved in. Emily thinks that now may be time to stop volunteering. If she is honest, Emily is not enjoying being out in all weathers and would like to spend more weekends with her family. But she still enjoys the sense of purpose that volunteering gives her.

PAUSE.

Is it best for Emily to step back from her volunteer role? Is this a red, amber or green situation? See page 69 to find out what happened next.

Answers for Emily



Challenge one: Green light

Emily spoke to her local event co-ordinator who suggested bringing a camping chair when she helps out and sharing a lift with another volunteer who lives nearby. She does not think it was necessary to step back from her volunteering role.



Challenge two: Amber light

Emily and the event co-ordinator arranged some time to discuss the situation. The co-ordinator thanked Emily for all her hard work and recognised that she had become a vital part of the team as she showed new volunteers what to do and had great organisational skills. Emily was given a new role, helping to plan events and train volunteers. She still goes to events, but only stays for half the day.



Challenge three: Red light

Emily talked it through with her family and the event co-ordinator. She has passed much of her knowledge and skills on to other volunteers so events now run very smoothly. Emily has now stepped down from this role.

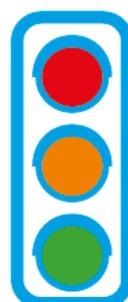
“I am proud to be part of Parkinson’s UK and enjoy talking about my volunteering. It’s a much bigger organisation than I first thought and I’ve discovered services and roles that I didn’t know existed.”

Clare, who helps review our volunteering policies

What can Fred do?

Select:

- Red to indicate that Emily/Fred need to stop volunteering within this role.
- Amber if Emily/Fred may be able to continue if some changes are made.
- Green if you think there's no problem.



STOP!

What needs to change?

Caution!

What might help in this situation?

Go ahead!

There is no real problem.

Challenge one

Fred has just started as a volunteer receptionist at a Parkinson's UK office. When he applied for the role, he said he was confident using a computer, but his IT skills are poor. Important telephone messages are not being passed on to people because he does not know how to send an email to more than one person at a time. He is putting pressure on himself and thinking about stopping volunteering.

PAUSE.

Is it best for Fred to step back from his volunteer role? Is this a red, amber or green situation? See page 71 to find out what happened next.

Challenge two

A few weeks later, colleagues notice that Fred is becoming very tired, arriving late and can sometimes be rude to members of the public who come into the reception office. Fred tells a member of staff he is now doing some casual bar work which means that he is getting little sleep.

PAUSE.

Is it best for Fred to step back from his volunteer role? Is this a red, amber or green situation? See page 71 to find out what happened next.

Challenge three

Fred has been offered a part time job. Although he loves his volunteering, he's unsure whether he'll be able to fit it in around his new job

PAUSE.

Is it best for Fred to step back from his volunteer role? Is this a red, amber or green situation? See page 71 to find out what happened next.

Answers for Fred



Challenge one: Green light

Fred sensibly asked a colleague to show him how to email more than one person at a time, and concerns about messages not being shared disappeared. Fred no longer thought that it was necessary to step back from his volunteer role.



Challenge two: Amber light

Fred talked to a staff contact about his problem and agreed to reduce the number of hours he covers the Parkinson's UK reception. His time keeping improved and his attitude was more positive.



Challenge three: Red light

After careful thought and discussion with his staff contact, Fred decided that he needed to step back from his volunteer reception role. All his colleagues were very grateful for the time and support he had given to Parkinson's UK.

“The main thing I have learnt through my volunteering is to accept the limitations caused by the condition more readily. My advice to new volunteers is go for it!”

Chris Ray, branch committee member

TOP TIPS

- 1** Speak to your staff contact if you would like further help or advice about how to manage your time.
- 2** Talk to other volunteers about how they manage their time. Some people make lists, others think about how much time they've got so they can say "no" if they need to. These methods might work for you too and you can also develop your own.
- 3** Share concerns about your volunteering with your staff contact. For example, if you're living with Parkinson's, you could discuss doing less volunteering if your symptoms change. If you have to step back from your role, it does not mean you need to stop supporting Parkinson's UK.
- 4** Consider other ways to support Parkinson's UK:
 - If you have an email address and access to the internet, visit our website to find out how to join our Research Support and Campaigns Networks
 - Call **020 7963 3912** for support to help you fundraise locally. Fundraising doesn't have to be complex. For example, you could ask people to donate to Parkinson's UK on your behalf for your birthday or wedding anniversary.
 - Make a regular donation to Parkinson's UK by calling **020 7932 1303** or, on your mobile phone, text PARKINSONS to **70500** to donate £5.
- 5** Look through our volunteering opportunities to find out more about what other things you can do for Parkinson's UK. We have volunteering opportunities all over the UK in local groups, at fundraising events, and through research and media work. If you have access to the internet, you can find these on our website at parkinsons.org.uk/volunteerroles. You can also talk to local staff and volunteers, call the volunteering team on **020 7963 9328** or send an email to volunteering@parkinsons.org.uk.

Congratulations you have completed your volunteer induction



“Volunteers make a massive difference in the lives of people living with Parkinson’s. So on behalf of the charity, the trustees, the staff, all of our members, everybody affected by Parkinson’s I want to say a massive thank you for the work that you do volunteering for Parkinson’s UK.”

Steve Ford, Chief Executive Parkinson’s UK

Thanks to the Parkinson's UK volunteers who helped write and review this induction.



Every hour, someone in the UK is told they have Parkinson's. Because we're here, no one has to face Parkinson's alone.

We bring people with Parkinson's, their carers and families together via our network of local groups, our website and free confidential helpline. Specialist nurses, our supporters and staff provide information and training on every aspect of Parkinson's.

As the UK's Parkinson's support and research charity we're leading the work to find a cure, and we're closer than ever. We also campaign to change attitudes and demand better services.

Our work is totally dependent on donations. Help us to find a cure and improve life for everyone affected by Parkinson's.

Parkinson's UK

Free* confidential helpline **0808 800 0303**

Monday to Friday 9am - 8pm, Saturday

10am - 2pm. Interpreting available.

Text Relay **18001 0808 800 0303**

(for textphone users only)

hello@parkinsons.org.uk

parkinsons.org.uk

*calls are free from UK landlines and most mobile networks.

PK0313

© Parkinson's UK, April 2015. (RD1780) Parkinson's UK is the operating name of the Parkinson's Disease Society of the United Kingdom. A charity registered in England and Wales (258197) and in Scotland (SC037554).