

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

DAILY LIVING EQUIPMENT FOR PEOPLE WITH PARKINSON'S



If you have Parkinson's, you may find it more difficult to do some of the everyday tasks and activities that you used to do easily.

This booklet looks at what equipment and gadgets are available, and how they may help you to feel more in control of everyday tasks. It also includes details of how to get the equipment and the funding options available.

This information was developed with help from researchers at King's College London, who carried out research about how equipment can help people with Parkinson's. The study looked at what equipment and gadgets are used by people with Parkinson's and their carers, and whether they helped increase people's safety, wellbeing and quality of life. We've included the equipment that researchers found was most popular and helpful for people with Parkinson's. You can find out more about the study on our website at parkinsons.org.uk/research

We cannot provide recommendations on specific pieces of equipment that you may need or find helpful. Parkinson's affects everyone differently and what suits one person may not suit another.

Equipment can also be expensive and is not always the answer to a person's needs. So get advice from an occupational therapist or your GP or Parkinson's nurse if you think you might benefit from a piece of equipment.

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CHOOSING EQUIPMENT AND ADAPTATIONS

Getting advice

Always get advice from an occupational therapist or physiotherapist before you buy equipment. Health professionals will have a better understanding of your condition than the person or company selling the equipment. Together you can discuss your needs and the options available to you before you make any decisions.

An occupational therapist can make recommendations based on your own requirements. These may involve exercises, changing the way you do something to make it easier, or other kinds of treatment. Often occupational therapists will prefer to help you by teaching you exercises and new ways of doing things, and may only advise that you buy equipment as a last resort.

Having an individual assessment will help you find the best solution for you. If an occupational therapist thinks you could benefit from using a piece of equipment, they may be able to provide or arrange changes

to your home (such as hand and grab rails in a bathroom) or suggest where to find suitable items. The Disabled Living Foundation can also give you independent information and advice on choosing equipment. See page 37 for contact details.

You can request an appointment for an occupational therapist to visit you at home through your GP or social services or social work department, or your local health and social care trust. Ideally you should be paired with an occupational therapist who has specialist knowledge of Parkinson's. This may not always be possible, but it's worth mentioning.

You can also be referred to other professionals, such as a physiotherapist, a specialist Parkinson's healthcare team or a rehabilitation service, if available near you.

You can choose to pay for private occupational therapy. To find a private occupational therapist

in your area, contact The British Association and College of Occupational Therapists. See page 37 for contact details.

Find out more: see our [information sheet *Occupational therapy and Parkinson's*](#).

Trying before you buy

If you decide to buy a piece of equipment it's best to try it out first. There may be different models available that you want to compare.

You may have an equipment demonstration centre near you that you can visit by appointment to view and try equipment. For details of your nearest centre, ask at your GP surgery or check the Disabled Living Foundation's website at www.livingmadeeasy.org.uk/contacts_edc



The Disabled Living Foundation also has an online tool, AskSARA, to help you identify suitable equipment and suppliers and compare products. Visit www.dlf.org.uk/content/asksara for more information.

Help with funding

Occupational therapists can give you advice and may be able to help arrange funding for minor home adaptations, such as fitting grab rails and handrails by stairs.

You can also get advice on more expensive home adaptations, such as stair lifts or accessible showers, from occupational therapists based in local social services or health and social care services.

If you need major changes to your home, such as an extension, fixed hoists, stair lifts or downstairs bathrooms and shower units, you may be eligible for a disabled facilities grant. If this grant is available, an occupational therapist will assess your needs and will contact the relevant council departments.

Funding for major home adaptations is often means tested. So the decision as to whether you get money from the government or local authority to help pay for something you need depends on

how much money you have, including your savings. To find out more about funding for major adaptations, see www.gov.uk/disabled-facilities-grants

Funding for equipment depends on the type of equipment and what funding is available in your local area or from other funding sources.

Some local Red Cross groups loan out equipment such as wheelchairs. See page 37 for contact details.

VAT

If you're disabled or have a long-term condition, you shouldn't be charged VAT on products designed or adapted for your own personal or domestic use. This includes stair lifts, adjustable beds, wheelchairs, alarms and building work, like installing ramps. You also shouldn't be charged VAT on installation, repairs, maintenance or spare parts for equipment.

Depending on your needs, you can apply for VAT exemption by:

- asking your supplier for a VAT relief form
- applying online when purchasing VAT-free items online
- downloading a form to take into a shop when you make a qualifying purchase

Visit www.gov.uk and search for 'VAT relief'. You can also call HM Revenue and Customs on **0300 200 3700** for more information.



GETTING AROUND

If you have Parkinson's you might experience symptoms that affect your ability to move around. There is a range of equipment available that you may find helpful.

Grab rails and handrails for stairs or walls

These are one of the most common adaptations that you may find useful. Extra stair and wall railings can give you more support and guidance in areas of your house where it's easier to fall, including staircases, corners or entryways. These rails can help you move around the house more independently.

Some people have rails installed to run horizontally across a room. This is particularly useful in the bedroom because you can use the rails to help with getting dressed or getting in and out of bed.

Handrails can be fixed vertically, from floor to ceiling, which you may find helpful for getting in and out of the bath, or beside a toilet where

lack of space means other rails won't fit. You might also want a rail placed somewhere suitable to help you balance when you do exercises.

Getting handrails installed

Speak to your Parkinson's nurse, occupational therapist or local council office to arrange an assessment from health or social services to see where hand and grab rails would fit in your home. Always get advice before fitting any rails to walls, so that they can be fitted in the best position, safely and securely.

You could also contact your local Age UK office, who may be able to assess your home and install rails at a small cost. Age UK's contact details can be found on page 37.

Walking sticks

Walking sticks are commonly used to improve balance and give extra support. Many people find that a stick helps them to walk independently. Although some people with Parkinson's actually find

that they can walk more safely without a stick, so it's worth trying them out first.

A walking stick can also be a helpful way to signal to others around you that you need extra room or time to move around. Some people with Parkinson's find this reduces anxiety caused by people crowding them, which could lead to freezing.

Types of walking stick

Wooden sticks – these have a set height and usually a curved handle.

Metal sticks – these can be extendable (height-adjustable), folding, collapsible, and three- or four-footed. They can have moulded or curved handles.

Nordic poles – these thinner, longer, lightweight poles can help you keep a more upright posture and increase your arm swing, especially if you are tall. They often have replaceable tips to suit different surfaces, such as pavements or soft ground.

Elbow crutches – some people find using two elbow crutches gives more support than a pair of traditional walking sticks, but crutches may not suit everyone.



Walking sticks with folding seats – these are larger and heavier than most other walking sticks, so may not be appropriate for everyday use. But they might be useful in situations where you want to take lots of breaks, such as for shopping or social events.

Lasercane – these are designed to help people with Parkinson's who experience freezing. The Lasercane projects a red laser beam onto the ground in front of your feet when walking. This cues you to step over the light when your feet freeze.

Some people find a Lasercane very effective, but it can be difficult to see the laser beam in bright environments, such as outdoors

on a sunny day or indoors in bright light. Also, studies have not proved that these canes provide consistent benefit.

For more information on the Lasercane, contact Attainability UK (see page 37 for details).

Other features – many walking sticks have different tips at the end, which can help with walking on rough, damp or icy ground and reduce the risk of slipping.

Choosing your walking stick

A walking stick should help you move more independently. If the stick is the right height, you will avoid problems with your balance and posture.

When choosing or adjusting your stick, wear your usual footwear. If you stand with good upright posture the handle should line up with the bump at the bottom of your wrist bone, with your arm hanging naturally at your side. This will mean that your elbow bends slightly when you hold the handle.

If you don't have much upper body strength, choose a stick that is light and easy to move forward in time with your stride. You may find the heavier three- or four-footed sticks are more difficult to move

forward and may trip you up. Choose a handle that is a shape and size that lets you grip it as strongly as you can.

Walking sticks are tested to a maximum weight, so check that yours is appropriate before buying.

Buying a walking stick

You might be able to borrow or be given a stick free of charge through the NHS, either from a physiotherapist, a Parkinson's clinic or your GP surgery. But they may have a limited choice of styles.

You'll have a much wider choice at most mobility shops and larger pharmacies. Here you can try different styles to find which is most comfortable and offers you the right level of support.

It's a good idea to look online at the prices of different walking sticks to compare with those you can buy in shops. Websites such as Amazon or eBay will list many sellers and brands of walking sticks. But check that any second-hand equipment is not damaged or unsafe in any way.

You may find it helpful to have two or three walking sticks, so that one can be kept on each level of your house and another for outdoor use.

Walking sticks should be regularly checked for wear and tear. If the tip of the stick (the ferrule) becomes worn, it must be replaced.

Walking frames

A walking frame or walker is a supportive frame used while walking. It can give you a higher level of support than walking sticks or rails, and can help you keep your balance, preventing falls. Many people find a walking frame helpful for short outings such as shopping.

Different types of walking frames can be used in different situations.

Ones without wheels are the most stable, but because they have to be lifted with each step they are usually only used for short distances. Three- and four-wheeled styles are better for walking longer distances, but there are different advantages and disadvantages for each.

A walking frame may help you keep your balance when getting up from a sitting position or when preparing to sit down. Using a walking frame can also increase your ability to get around on your own.

Types of walking frame

Non-wheeled walking frame

– these may have an adjustable height and can be made of different materials. They are usually a lightweight metal alloy, but make sure the walking frame is light enough for you to lift and move forward easily.

Collapsible or folding walking frames

– these are easy to store either at home or in the car when travelling.

Wheeled walking frames

– these may have two, three or four wheels. Small, hard wheels are lighter and good for smooth surfaces, while larger tyre-style wheels are heavier and better for rougher surfaces.

Other features

– wheeled walking frames often have a fixed or folding seat, which may be useful to rest on during walks. But sometimes people find the seat gets in the way or adds too much weight to the frame, making it difficult to push or move around. Some walking frames have baskets under the seat or on the handle bars, which can be helpful for carrying things.

Choosing your walking frame

Make sure your walking frame is at the right height for you. The Disabled Living Foundation guidelines say that the hand grips should be at wrist height when the elbow is slightly bent (see the instructions on page 11 for setting the height of walking sticks).

Before buying a walking frame, think about where you will want to use it. For example, will it fit through doorways when you're at home?

If you are of a larger build, it is possible to get wider walking frames. These also come in lightweight versions that are easier to push.

Four-wheeled walking frames tend to offer more support than three-wheeled ones because they are wider and are usually made of heavier materials. This makes them particularly good for taller or heavier people, and also people who tend to fall over more often or who experience involuntary movements (dyskinesia) or tremor. But heavier frames may be more difficult to use, and to lift in and out of cars.

You may find some walking frames more difficult to push than others.



If possible, try lots of different styles to see which allows you to walk most naturally. Sometimes a walking frame may 'get away' from the person using it and cause them to fall. There are different types of brakes available. Make sure they are easy for you to use, as some can be difficult if you experience rigidity or weakness in your hands.

You may find it useful to have two or even three walking frames so that one can be kept on each level of your house, and possibly another stored in your car boot for use away from home.

Buying a walking frame

It may be possible to borrow or be given a walking frame through the NHS, either from a physiotherapist, a Parkinson's clinic or your GP surgery. But they may have a limited amount of choice.

Mobility shops and larger pharmacies will stock a range of walking frames that you can try to find out which is most comfortable and provides you with the right level of support.

Manual wheelchairs

Some people with Parkinson's do not want to use a wheelchair all the time, but keep one in their home for when they are having a bad day

or in their car for when they go on longer outings.

Some people also find wheelchairs a good way of exercising because they can push it, use it as a walking frame, and sit in it when they get tired. Manual wheelchairs may be moved by the person sitting in the chair (self-propelled) or pushed by someone else (attendant-propelled). In both cases, the person moving the wheelchair will need a fair level of strength and fitness.

Types of wheelchair

Collapsible wheelchairs – many wheelchairs are collapsible, with removable wheels. This can help you to store the wheelchair more easily at home and in your car. It is also possible to get a folding backrest with handles that fold down.

Detachable chairs – some wheelchairs have seats that detach from their base so you can slide the seat onto a base in the car. This means that there is no need for the person sitting to transfer between seats.

These are usually quite expensive and heavy, so they require some strength to move between the seat bases. They also require a hoist operated by

another person to move the base into the boot of the car.

Power packs – many people attach a power pack to the bottom of their manual wheelchair, which means that less force is needed to push the chair. This can be a good option for longer outings, but because it can be difficult to attach, it may not be useful for very short journeys. Also, power packs for manual wheelchairs don't fit all wheelchairs.

The pack is attached quite low to the ground, so it can get caught on steep ramps and other surfaces.

Comfort and safety tips

- Always apply the brakes when the wheelchair is not moving.
- Adjust the footplates to the correct height so you can sit comfortably and move them out of the way when you are getting in or out of the chair.
- A suitable cushion can be used in a wheelchair to prevent excess pressure if you feel discomfort from sitting for over half an hour.

Choosing your wheelchair

Look for a wheelchair that:

- is not too heavy to lift, and collapses easily if you or

someone else will be putting it in the car regularly

- has handles at a height that means the person pushing the wheelchair doesn't have to stoop down to reach them
- has large enough wheels to go over kerbs easily
- has anti-tipping features, if tipping out of the chair is a concern. A lap strap can be a good idea to help keep you safe, especially when going over kerbs or single steps

Buying a wheelchair

Ask your GP or local hospital if they have wheelchair services. You may also qualify for credit towards the cost of a wheelchair if you want to buy one yourself.

Wheelchairs are often available to hire or buy from charities such as the Red Cross (see contact details on page 37). You can try before you buy by borrowing different wheelchairs from mobility centres or shop mobility schemes, where electric wheelchairs are available for short-term hire to use in large shopping areas.



PERSONAL CARE

Bathing and showering

Some people with Parkinson's find bathing or showering difficult. People have told us they are concerned about slipping and falling. And family or carers can find helping a person out of the bath or shower difficult.

Grab rails are a very useful aid in bathrooms and toilets because they can help give you stability and confidence. You can find out more about grab rails in the Getting around section of this booklet, on page 9.

It is also a good idea to apply a slip resistant material to the bottom and edges of the bath or shower, as well as to railings. Shower heads on a hose are useful as then you can get the water exactly where it's needed.

Bath and shower seats

Bath and shower seats can help you get in and out of the bath with less risk of falling. They also mean that carers don't have to do any heavy

lifting if you need help. Some people find these seats help to reduce problems with their balance when standing in the shower.

There are two main types of bath seat available. The first sits across the top of the bath, either as a seat or a simple board. This can either be removable or attached to the wall on a hinge. The second type is normally more complex and can be lowered into the bath manually or electrically.

If you have a shower cubicle, you can use a free-standing stool or mount a 'flip-down' seat on the wall. Many styles are available, from small, simple waterproof stools to large electrically powered seats. The one that is best for you will depend on the type of shower or bath unit you have, and your own preferences.

Converting a bath to a shower or wet room

Some people convert their bath tubs to shower units or wet rooms

that contain a shower. They may also add a bathroom to the ground floor of their home if they find it hard to climb stairs. In some cases, it may be easier to convert a small bedroom or large storage area into a shower room instead of replacing a bath.

Some people with Parkinson's find that a shower with a suitable seat and grab rails makes washing much easier, especially if the shower floor is level with the bathroom floor.

Make sure handrails are in good positions to help with balance and walking in or out. Anti-slip tiles or adhesive anti-slip material on the floor can prevent slipping when the floor gets wet during your shower.

As with any major building work in the home, these kinds of conversions can be expensive. Talk to an occupational therapist about whether converting your bath into a shower or wet room would be a good idea for you.

[Paying for a bath-to-shower conversion](#)

It may be possible to get some funding to pay for your conversion. Speak to an occupational therapist or your local council, social services or Parkinson's local adviser about grants.

“We have just had a remote-controlled walk-in shower installed. The advantage of this is that you set flow and temperature before entering the shower, so that you do not get initially drenched with cold water. It also doesn't need a door, which can be a pain to people with Parkinson's. It wasn't cheap, but for me the advantages justify the cost.”

Andrew

[Using the toilet](#)

Some people with Parkinson's find using the toilet difficult. They can find it hard to sit down with confidence and to get up from a seated position, especially if the seat is lower than knee level. Many people with Parkinson's also find they need the toilet more often and more urgently. But there is equipment that can help.

[Raised toilet seats](#)

A raised toilet seat can help you get up more easily from a seated position on the toilet. Many people find this a key piece of equipment to help them maintain their independence.

When choosing a raised toilet seat, make sure the seat is large enough for you to sit comfortably and avoid leakage. Make sure the seat isn't too high for other people in the house and that it can be safely removed and replaced.

[Toilet grab rails](#)

A grab rail can help you get on and off the toilet. It can also help with balance problems while standing and using the toilet. There are different grab rails to choose from, including free-standing rails and hinged drop-down rails that fix to the wall behind the toilet.

Toilet grab rails are usually supplied by social services or the social work department. The type of rail that is best for you will depend on:

- whether a fixed rail will fit the area around your toilet
- whether it will be at the appropriate height
- whether you will need to adjust the rail at all

Speak to an occupational therapist or Parkinson's nurse to find out which type will suit your needs and how best to get one.

For information on installing grab rails elsewhere in your home, see page 9.

[Other equipment](#)

Various hand-held urinals are available for both men and women. They may be useful if you need to urinate urgently, but can't get out of a bed or chair quickly enough. Some people use commodes if they find that they need the toilet urgently or often. This means that they don't have to walk far at night.

You can also buy discreet disposable pads to place in your underwear to help manage incontinence. Some men with urinary incontinence prefer to use a sheath. These fit over the penis and collect urine in a leg bag.

Items like these are often available from specialist continence nurses or services, district nurses or with a GP prescription.

Find out more: see our booklet [Looking after your bladder and bowels when you have Parkinson's](#).



GETTING IN AND OUT OF BED

If you find getting in and out of bed difficult, there is a range of equipment available to help you and your carer, if you have one.

Satin sheets

The shiny material of satin sheets can help you to turn over in bed. You can buy specially designed sheets with satin panels or off-the-shelf satin sheets. Some people prefer to just have a panel of satin going across the middle of the bed where their hips would rest. Single, double and king-size bed versions are available.

Wearing satin pyjamas may also help, but try not to use satin sheets and satin pyjamas at the same time. Together, they can increase the risk of sliding out of bed too quickly.

If you use satin sheets or panels, make sure there is an area of friction either at the end or sides of the bed, so you can get some grip. Your Parkinson's nurse or occupational therapist should be able to give you advice.

Bedside grab rails

You can use these specially developed rails to adjust your position when in bed, to help yourself out of bed and to lower yourself into bed independently. A grab rail on a wall along one side of a narrow bed may help you to roll yourself over at night.

You will need moderate upper body strength to be able to use bedside grab rails and an occupational therapist or physiotherapist will be able to show you the easiest ways to use them.

Bed raiser

Bed raisers are used to raise the whole bed a few inches, making it easier to get in and out of bed. Bed raisers come in various heights, usually between three and six inches, and different materials such as wood, plastic and metal, to match the existing bed legs.

Make sure your bed raisers are stable and well supported. Also make sure that the legs of your

bed sit deep within the bed raisers and do not just rest on top of them where they may slip off.

Mattress raiser

A mattress raiser can help lift you up into a seated position, helping you to get out of bed.

Types of mattress raiser

Mechanical – these can be set to a certain degree of elevation but can't be repositioned easily.

Electric – these allow you to raise and lower the bed using a handheld control.

Pneumatic – these use air to inflate a pillow-like device under the mattress to raise and lower it. This can also be set to inflate only on one side, turning you at the same time.

Choosing your mattress raiser

Raisers are more effective if the mattress is fairly thin. Thicker mattresses are difficult to bend and can scrunch up in the middle, which can be uncomfortable and make it more difficult to get out of bed.

Check that the controls are simple – single button controls might be easier. Also check whether the mattress raiser is likely to be noisy.

Comfort and safety tips

- Make sure electric cords, feeding lines or bedding won't get caught up when the raiser is in motion.
- If your bed has a bedside rail or bed lever, it should be positioned so that it goes up and down with the mattress.
- Be aware that in the raised position, a mattress raiser can cause you to slide down and out of the bed!

Electric profiling or hospital bed

An electric profiling or hospital bed is a piece of equipment that can be used to help you sit up from lying down. Some people find it reduces dizziness caused by lying too flat and that it reduces ankle swelling.

Hospital beds are usually height-adjustable and may have side rails. They may have casters or wheels, which allow the bed to be moved from room to room. Electric profiling beds tend to look more like an ordinary bed. Both types of bed usually allow you to raise and lower the mattress at the head and knees.

If you have a partner and they want the bed in a different position, some styles are available that split



the mattress. This means each person can adjust the mattress to the position they want.

As these beds can be quite expensive, speak to an occupational therapist before you buy anything.

Comfort and safety tips

- Make sure there are no electric cords, feeding lines or bedding that will get caught up when the mattress is being raised.
- Take extra care if the bed has heavy sides that go up and down as it may be easy for your fingers and hands to get caught, especially if the rail comes down suddenly.

- Make sure the controls can be reached easily when you are lying down.

Mobile hoist

A mobile hoist can be used to lift you between your bed and wheelchair, or your bed and a commode. It is usually a piece of equipment that social services will provide or recommend.

There are several different types available. You can discuss with an occupational therapist whether this equipment is suitable for you.

Find out more: see our booklet *Sleep and night-time problems in Parkinson's*.

Over-bed trapezes and rope ladders

There are bars (over-bed trapezes) and ropes that can be hung over the bed where your head lies. These allow a person to pull themselves up from a lying to a sitting position.

You need a lot of upper body strength to use these devices so they don't suit most people with Parkinson's. An occupational therapist will be able to advise you about whether this piece of equipment is suitable for you.

Find out more: See our booklet *Sleep and night-time problems in Parkinson's*.

COMPUTERS AND MOBILE PHONES

Some people with Parkinson's find that they have difficulties with communication, including their speech and writing. But lots of gadgets are available that can make this easier.

Computer (desktop or laptop)

Being able to use a computer and the internet can open up lots of opportunities for you. You can:

- handle day-to-day correspondence through email, video calling or using speech-to-text software, which can be useful if you have problems writing by hand
- keep in touch with your friends and family, and share experiences with other people affected by Parkinson's through online communities and social media
- search for information about Parkinson's and other subjects of interest

- manage your online banking and shopping, which can save time and may be helpful if you have limited mobility or live in a remote area
- enjoy leisure time – such as artistic or other hobby interests by finding like-minded people and resources online

Mobile phones

For many people, having a mobile phone offers peace of mind as they know that they can contact someone straight away in an emergency.

Smartphones (a mobile that acts as a small computer and connects



with the internet) come with apps, which are pieces of software that can be used to perform specific tasks, such as writing a note or playing a game. Smartphones have many different apps that you may find useful, including:

Voice activation – most smartphones either have built-in features to enable voice control, or you can install an app to do the same job. You can use voice activation to help you:

- call someone in your phonebook just by saying their name
- search the internet
- dictate text messages and emails
- open applications
- record notes as reminders or to send as messages

Global Positioning System (GPS) trackers – these allow a nominated person, such as a partner, family member or carer, to see on a map where you are (as long as you are carrying your smartphone and are not in a signal black spot).

Video calling – lets you see and hear each other during a call.

Medication managers – to remind you when your medication



is due. They may also let you store medical information, for example care plans, details of local healthcare professionals, local resources, etc.

Data gathering apps – can be used to measure some movement symptoms and speech. These can then be used to inform the person who adjusts your Parkinson's medications or treatments.

Find out more: see our [information sheet *Using computers and the internet.*](#)

PERSONAL EMERGENCY ALARMS AND MONITORS

If you experience falls, it may be useful to carry a personal alarm. Personal alarms can also help give partners and other family members peace of mind if they are concerned about someone when they are alone.

Types of alarm

Pendant alarms – a very popular choice, these are worn around the neck or wrist. When activated they send a signal to either a unit in another part of the house, the phone of a nominated emergency contact or a call centre. A wrist watch style call button is also available for some alarm systems.

Monitors and intercoms – you can use these to alert another person in your house if you need them. Some monitors are triggered when you walk past them, for example if you get out of bed in the middle of the night, the monitor will play a voice message. Some pendant or clip-on alarms are also triggered if you fall or if smoke is detected.

Wireless doorbells – these are available from any hardware shop and can be useful to create a low-cost portable call system for your house and garden. This may be useful if your voice is not strong enough to call for help from someone nearby.

Mobile apps – some specialist mobile phones and apps for smartphones can act as an alarm trigger, or a combination of a falls monitor and automatic alarm trigger.

Community alarm systems – using a combination of different alarms and falls monitors, you can create a community alarm system.

Some alarm systems connect to a call centre. They use two-way speakers in the house so that a call handler can ask if the person who triggered the alarm is OK. If there is no answer or the person reports that they need help, the call handler can arrange urgent assistance from either an appointed contact, such

as a relative or neighbour, or from the emergency services.

Buying a personal alarm or monitor

You may be able to get a personal alarm or monitor from your local council or from a charity. But this may mean you don't get a choice of model. You can usually get help towards the cost of alarms or monitors where the device links you to an emergency call centre or other support to help you in a crisis.

Find out more about where to get alarms or monitors by speaking to your GP, specialist or Parkinson's nurse.

There is also more information from the Disabled Living Foundation at www.livingmadeeasy.org.uk



MANAGING MEDICATION

While there is no cure yet for Parkinson's, there are many different drugs that can help you to manage your symptoms. Some people with Parkinson's have a complicated regime, taking a number of different medications at different times of day. It can therefore be helpful to use medication management gadgets.

Pill organisers with timers

Pill organisers are used to arrange and store medication, which helps you to make sure that you are taking the right medication and dose at the right time.

Types of pill organiser

Pill organisers – these often have separate compartments for several doses per day. This can range from seven to 28 compartments. As people with Parkinson's typically take their medication four times a day, the larger 28-compartment devices can cover a full week. If you need more compartments, you can use two pill organisers.

Pill organisers come in different shapes. The more traditional, square box usually has the days of the week horizontally and doses per day vertically. Newer, round boxes are designed to rotate on a disc with compartments on the outer edge.

Dosette boxes – these organise medication by the day of the week and time of day. They can be empty boxes that you refill weekly or may come pre-filled by your pharmacist. These dosette-style blister packs are already organised into times and daily doses, according to your prescription.

Dosette boxes usually have 21 or 28 separate compartments so, depending on the number of times a day you take medication, these may cover one week per box. Some people find having two dosette boxes allows for easy exchange and refills at the pharmacy.

Automatic pill dispensers – these allow you to set the organiser to

“ I tend to forget when my medication is due so I have a watch which vibrates when my meds are due. This saves alerting the world at large that I am about to take my pills. ”

Jill

‘unlock’ one compartment at a time. This makes sure you are aware when a dose is due and makes it easy to take the right amount of medication.

Travel-size pill timers – these portable devices can hold a small number of medication doses (usually enough for a day) and have a small alarm to remind you when to take your medication. They can be useful to carry what you need when you are out and about.

Medication alerts – these will tell you when to take your medication through sounds, vibrations, flashing lights or a combination of these. Some advanced devices can send a text message to an emergency contact number if you don't take a dose within a specified timeframe.

Many people find that timers on mobile phones or digital watches

are more useful than pill timers or pill organisers. Some people prefer vibrating timers, rather than beeping ones, because they draw less attention in public.

Choosing a pill organiser

If you have difficulty using your hands or problems with fine finger movements, you might prefer to choose a design that has larger buttons and compartments. Simpler pill organisers may also be better if you have difficulty with your memory and thinking.

Look for alarms that are easy to set and that reset automatically in preparation for the next dose. Many have ‘pre-set’ alarms that repeat daily, which may or may not be suitable, depending on how regularly you take your medication.

Blister pack pill ejectors

A pill ejector is used to push a pill out of its packaging. It's a small plastic device that lets you apply more pressure to the packaging than you could with your hands.

Try not to break pills when using a blister pack pill ejector. It's also useful to make sure there are no stickers or labels on the back of the blister packs, which will make it more difficult to push the pills through.

Pill cutters

Pill cutters can be used to split pills into smaller sections, which make them easier to swallow. These are usually combined with a small plastic container that allows you to place a pill in a slot and cut it cleanly in two. The lid contains a razor sharp blade that comes down to cut the pill in half, so it's important to use the cutter correctly and safely.

Pill cutters do work very well and can be more precise than trying to snap pills in half. However, there are several issues to be aware of:

- Controlled release or modified release tablets (eg Sinemet CR, Ropinirole XL, Pramipexole PR) should not be broken or cut as this will interfere with the controlled release mechanism.
- Madopar capsules should not be split – if splitting is needed, it would be better to have dispersible Madopar tablets.
- Entacapone or Stalevo can be split to enable swallowing but the ‘raw’ edges taste unpleasant.



EATING AND DRINKING

If you find it difficult to make and eat drinks or meals, it's worth considering specialist items that could help.

Specially designed cutlery

If you have reduced grip, weakness or tremor, it can be difficult to handle cutlery. Several specially designed styles are available, including:

- an all-in-one knife and fork
- an all-in-one fork and spoon
- special handles that are extra-large, easy-grip (moulded rubber), extra-light, weighted or curved
- foam sleeves, which can be placed over existing cutlery handles to make them easier to hold
- Cutlery which can be bent to suit different grips

You can usually buy specially designed cutlery in high street mobility shops. If possible,

experiment with the different types to see which you find helpful.

If you experience stiffness and rigidity, you may find that extra large or curved-handled cutlery works best for you. If you have a tremor you may prefer the combined fork and spoon or a heavier item, or utensils with moulded rubber handles for extra comfort.

Food preparation knife

If you have difficulty gripping things, a curved-handled or rocking action knife can be used for chopping food. The handle is D or L-shaped to help give you more control.

They come in various sizes and the handles are usually made from easy-grip material.

Plate guard

Plate guards can stop food from falling off the edge of your plate. They clip onto the plate and provide an upright ring around it.

You can also push food up against the guard to get it onto your fork or spoon.

They come in different sizes, colours and materials but generally fasten to the plate edge, acting as a barrier. Some are positioned about an inch in from the outer edge of the plate, but these can decrease the usable area of the plate.

Some people prefer styles made of sturdy materials that are easier to wash.

Sip and nosey cups

If you have a tremor, using a sip or sports cup with a lid will help stop liquids from spilling. Some people use a hydration system that connects a bottle of drink by a short narrow hose (usually used by cyclists and other sports people) so that sips can be taken when you want, with very little effort.

Nosey cups have a section cut out on one side, opposite the position of the mouth when drinking. The cut-out allows the person drinking to tilt and drain the cup more easily with limited neck movement. These cups are made of plastic so are only suitable for cold drinks.

Sip and nosey cups come in different sizes, colours and shapes,

and may or may not have handles. If the sip cup is being used for hot drinks, it's important to make sure it's made of a material that won't soften or melt.

Non-slip mats

You can place a mat made of a special tacky material under a plate or bowl to stop it from moving around while you eat. This can be especially useful if you have limited mobility in one arm and find yourself chasing your plate across the table.

Non-slip mats can also be used on a tray to stop cups sliding during carrying, and between a mixing bowl and a work surface to stop the bowl moving.

Non-slip mats come in a range of colours. They may be pre-cut in placemat styles, or you can buy the material by the metre and cut it to the size you need.

Kettle tipper

A kettle tipper lets you pour boiling water out of the kettle without lifting it up, which reduces the risk of spills and burns. They are usually designed to cradle your kettle, and can be used on different common teapot or kettle styles. Check compatibility with your kettle before purchasing.



Boiling water dispensers or built-in taps

Water dispensers are used for dispensing boiling water without a kettle or saucepan. They allow you to fill a cup or mug with a pre-measured, cup-sized amount of boiling water. These are fairly easy to use, but must be filled manually and only supply small amounts of boiling liquid at a time.

Built-in hot water taps are a more effortless yet expensive option, and need to be installed and connected to a water supply. A built-in tap can be used for dispensing larger quantities of boiling water, without having to refill a dispenser. This allows for easy access to as much boiling water as you need.

GOV.UK

Website of the UK government, with information on public services and sections specifically for carers.

www.gov.uk

Motability

The Motability Scheme helps disabled people exchange their mobility allowance for a car, scooter or powered wheelchair.

0845 456 4566

www.motability.co.uk

Parkinson's UK online shop

We sell our own range of daily living aids. You can have a look at the online shop, where you can also order a Daily Living Aids catalogue.

0844 415 7863

parkinsons.org.uk/shop

Shop Mobility

Shopmobility schemes, based at shopping centres throughout the UK, provide short-term hire of wheelchairs and scooters to help you get around the shops. Details of which shopping centres near you provide this service can be found on their website, or by calling them.

01933 229 644

nfsuk.org

Turn2us

Use the Turn2us Benefits Calculator and Grants Search for information about sources of grant funding for people affected by Parkinson's.

www.turn2us.org.uk/Find-Benefits-Grants

Parkinson's nurses

Parkinson's nurses provide expert advice and support to people with Parkinson's and those who care for them. They can also act as a liaison between other health and social care professionals to make sure your needs are met.

Parkinson's nurses may not be available in every area, but your GP or specialist can tell you about local services.

You can find out more at
parkinsons.org.uk/nurses

Information and support from Parkinson's UK

You can call our free confidential helpline for general support and information. Call **0808 800 0303** (calls are free from UK landlines and most mobile networks) or email **hello@parkinsons.org.uk**

Our helpline can also put you in touch with one of our local advisers, who provide one-to-one information and support to anyone

affected by Parkinson's. They can also provide links to local groups and services.

Our website has information about your local support team and how to contact them at **parkinsons.org.uk/localtoyou**

You can find details of our local groups and your nearest meeting at **parkinsons.org.uk/localgroups**

You can also visit **parkinsons.org.uk/forum** to chat to other people with similar experiences on our online discussion forum.

Thank you to everyone who contributed to or reviewed this booklet:

Ana Aragon, Independent occupational therapist and Associate Senior Lecturer

Lyn Norkett, Occupational therapy advanced practitioner

Keren Worsley, Disability Living Foundation

Thanks also to our information review group and other people affected by Parkinson's who provided feedback.

All of the photographs in this booklet feature either people affected by Parkinson's, health and social care professionals involved in caring for people with Parkinson's or Parkinson's UK staff. Thank you to everyone involved for letting us use their photograph.

We make every effort to ensure that our services provide up to date, unbiased and accurate information. We hope that this will add to any professional advice you receive and help you to make any decisions you may face. Please do continue to talk to your health and social care team if you are worried about any aspect of living with Parkinson's.

If you'd like to find out more about how we put our information together, including references and the sources of evidence we use, please contact us at publications@parkinsons.org.uk.

How to order our resources

0845 121 2354

resources@parkinsons.org.uk

Download them from our website at parkinsons.org.uk/publications

Can you help?

At Parkinson's UK, we are totally dependent on donations from individuals and organisations to fund the work that we do. There are many ways that you can help us to support people with Parkinson's.

If you would like to get involved, please contact our Supporter Services team on **0800 138 6593** or visit our website at parkinsons.org.uk/donate. Thank you.

Daily living equipment (WB22/2017)

Do you have any feedback about this information? Your comments will help us ensure our resources are as useful and easy to understand as possible. Please return to Information Content team, Parkinson's UK, 215 Vauxhall Bridge Road, London SW1V 1EJ, or email publications@parkinsons.org.uk. Thank you!

1. Please choose the option that best fits you.

- I have Parkinson's and was diagnosed in
 - I care for someone with Parkinson's
 - I have a friend or family member with Parkinson's
 - I'm a professional working with people with Parkinson's
 - Other (please specify)
-

2. Where did you get this information from?

- GP
 - Specialist
 - Parkinson's nurse
 - Parkinson's UK local group
 - Parkinson's UK local adviser
 - Ordered directly from us
 - Call to the helpline
 - Other (please specify)
-

3. Has it answered all your questions?

- Yes, completely
- Not sure
- Yes, mostly
- Not at all
- Partly

4. How easy was it to understand?

- Very easy
- Quite difficult
- Easy
- Very difficult
- Not sure



5. Has it helped you manage your condition better, or make choices that have improved your life in some way?

- It helped a lot It didn't help
 It helped a little It made things worse
 No change

6. What is your ethnic background?*

- Asian or Asian British Mixed
 Black or Black British White British
 Chinese White Other
 Other (please specify)

*We ask about your ethnicity to ensure our information is reaching a broad range of people. However, this question is optional.

Want to hear more from us?

- I would like a response to my feedback
 I would like to be a member of Parkinson's UK
 I'm interested in joining the Information review group, to offer feedback on Parkinson's UK information

If you've answered yes to any of these options, please complete your details below.

Name _____

Address _____

Email _____

Telephone _____

How would you prefer us to contact you?

- Email Post Phone

We will not pass on your details to any other organisation or third party. To find out more, read our privacy policy at parkinsons.org.uk/termsandconditions

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Every hour, someone in the UK is told they have Parkinson's – a brain condition that turns lives upside down, leaving a future full of uncertainty.

Parkinson's UK is here to make sure people have whatever they need to take back control – from information to inspiration.

We want everyone to get the best health and social care. So we bring professionals together to drive improvements that enable people to live life to the full.

Ultimately, we want to end Parkinson's. That's why we inspire and support the international research community to develop life-changing treatments, faster. And we won't stop until we find a cure.

**Together we can bring forward the day
when no one fears Parkinson's.**

Parkinson's UK
215 Vauxhall Bridge Road
London SW1V 1EJ

Free confidential helpline **0808 800 0303**
(Monday to Friday 9am–7pm, Saturday 10am–2pm).

Interpreting available.

NGT Relay **18001 0808 800 0303** (for use with smart phones, tablets, PCs and other devices). For more information see **www.ngts.org.uk**

hello@parkinsons.org.uk
parkinsons.org.uk

Order code: WB22

Last updated 2017. We review our information within three years. Please check our website for the most up to date versions of all our information.

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