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A CARER'S GUIDE TO PSP & CBD

INTRODUCTION

Welcome to the PSPA Carer's Guide. We hope you will find helpful advice, support and inspiration in these pages. Here at PSPA we recognise the immeasurable value of carers, the complexities that can come about in caring for a loved one with PSP or CBD, and the importance of caring for the carer too. Throughout this publication you will find the voices of many carers passing on their wisdom, knowledge and encouragement. It also details what further assistance is available, and how to connect with others in similar circumstances. Together we can create a better understanding and future for everyone affected by PSP & CBD.

Jacqueline Ede, PSPA Carer Support

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BEING A CARER

Welcome to the PSPA Carer's Guide. We hope you will find this a helpful resource.

AM I A CARER?

You may not readily think of yourself as a carer because looking after your loved one is about so much more than doing a job, it is the continuation of your relationship, your commitment to another person. Many carers don't see themselves as carers, with research showing that it takes people an average of two years to acknowledge their role as a carer (NHS, 2023). There is also the question of am I *becoming* a carer?

A carer can live with a person receiving care or be at a distance, they may be family members or not, they can be young people, adults of working age or retired.

> **"My dad had PSP and with my siblings we supported him for a few years. In our situation if you asked my brother, he would have said he wasn't a carer as he thinks of a carer as someone who is paid or is a spouse/partner"** *Jen, 44*

In UK law those who are providing unpaid care are formally acknowledged through the definition that, "a carer is anyone, including children and adults who looks after a family member, partner or friend who needs help because of their illness, frailty, disability, a mental health problem or an addiction and cannot cope without their support"(Gov't, 2014). The charity Carers UK have found there are 6.5 million people who are unpaid carers, with 1.4 million providing over 50 hours of care per week.

> **"Very few family carers ever receive any formal training, and it is a question of learning on the job, just like bringing up children. We reflect on how our parents guided us through growing up, but not many people have experienced how to care for a family member with life changing health conditions. Occasionally you may get it wrong. The most important thing is don't be disheartened with the occasional failures, most of the time you get it right"** *Paul, 76*

REGISTERING AS A CARER

How you are formally recognised as a carer differs across the four UK nations. Your GP surgery will either make a note on your records or ask you to complete a registration form. If using a form, there are Young Carer and Adult Carer versions available. This enables you to access your first line of support with your doctor and means the surgery may be able to give you tailored assistance, for example:

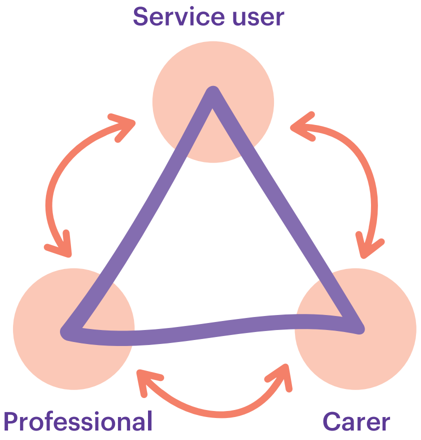
- Booking double-appointments for you and your loved one to save two trips if you share the same GP
- Putting you on the list to be invited for an annual health check and to book vaccinations such as the flu jab
- Acknowledging that symptoms you present with may be linked to the physical and mental impact of your caring role and provision of carer help
- Making referrals to services, which may support you, including carer respite break payments
- Greater involvement in appointments and care planning.

> **"I always say I fell into caring, rather than it being a conscious choice"** *Allison, 60*

Being formally recognised can also support further applications and access to other help both for yourself and when you are acting on behalf of your loved one.

> **"Last year when my husband was diagnosed with PSP and his support needs increased, I started to ask myself if I was becoming his carer. I had known the importance of unpaid carer organisations throughout my nursing career but had always denied that I was a carer even when my husband started to lose his eyesight 25 years ago. I decided to contact PSPA and our local carer's centre. I had a carer's support plan completed and now receive amazing emotional support, information and advice, access to benefits and grants and break times for me. The best decision I ever made was registering as a carer"** *Christine, 76*

TRIANGLE OF CARE



Adapted from the Carers Trust, 2010

Following resounding research evidence that carers need to be consulted with and listened to more, The Carers Trust led a national project to create a therapeutic, workable model of support for better practice, known as the Triangle of Care.

The Triangle of Care, which has been adopted by health and care providers across the UK, acknowledges the valuable role of unpaid carers, reflecting the benefits when service users, carers and professionals work collaboratively towards the best outcomes for care, promoting safety and wellbeing, and supporting good communication. It has created a standard of involvement, which carers can expect and request.

CARER'S ASSESSMENT

No matter how long you have been caring, who for, what tasks you do, whether you live with them or not, everyone in the UK is entitled to a carers assessment, called a Carer Support Plan in Scotland or a Carer Needs Assessment in Wales.

A carer's assessment is not to check how good you are at caring, it looks at:

- Your caring role and how it affects your life and wellbeing
- Your health
- Your feelings and choices about caring, and whether you would like counselling to work some of this through
- If you are working, what support you have from your workplace
- Any issues about your accommodation and living arrangements
- Financial benefits like council tax reduction and carer allowances
- Legal issues such as getting lasting power of attorney in place
- Sources of support like local activities, services and support groups
- Community transport use and the blue badge scheme
- Options for respite and regular breaks in the week
- Planning for emergencies if at anytime there is a crisis and you are unable to care.

> **"You might not think you need it now, but ask for help at the very beginning because these things take longer than you expect"**
> *Maggie, 64*

You have a choice for where you can get a carer's assessment. This can be via your council's social services or your local carer's association. Every county or borough area, by law, has to commission carer support for adult carers and young carers. Depending on where you live, different organisations will have the contract. Search the internet or call the council to see who this is in your area.

Carer's assessments should aim to acknowledge the effect your role is having and what may support you. Think about whether you need anything right now and ask about what is available ahead.

Consider how things are and what could make the situation easier for you. When was the last time you had a day to yourself? Do you want some extra help with some of the care or domestic tasks you do and if so which ones? Are you feeling isolated and need more time with others for support? Do you need some time to deal with your own health? If you were suddenly unable to care, what would you want the plan 'b' to look like? You could write some questions down ready.

The first carer's assessment doesn't have to be your one and only; as things change this can be reviewed when you think it might be helpful to have a review of what you need.

WORKING CARERS

There are 3.7 million working carers in the UK, with the vast majority reporting they struggle to combine work responsibilities and caring commitments. Support can be expected from the workplace and you are protected from discrimination under equalities and rights legislation. However, many are reluctant to raise the topic of being a carer because they believe nothing would change if they did. They may not want to raise personal issues at work, or it might not be the sort of thing people talk about, or there is fear it will cause problems (CIPD and University of Sheffield, 2020).

Although your manager may know unofficially, registering as a carer (see page 5) gives you formal documentation to pass to your employer and start a conversation about your caring role in relation to work and contingency plans. Company policy or job contracts may outline what adjustments are available. You could explore trialling flexible hours, start and finish times, crisis or carers' leave, home and hybrid working options.

SELF-EMPLOYED

For those who are self-employed, you may wish to consider income protection insurance to cover times of increased need or crisis. Being independent of a manager doesn't mean you don't have contractors to report to, and open conversations around short notice timings and deadlines may be appropriate.

SUPPORT FROM OUTSIDE OF WORK

If you work and provide care for more than 35 hours a week, you are eligible for carer's allowance. You can also apply through your local council for respite or 'short break' care if you need someone to help look after your loved one while you are at work. This could mean having a paid carer or a regular day centre place made available.

SHOULD I CONTINUE WORKING?

Continuing to work can give carers an alternative focus, keeping connected to other people, maintaining continuity, having career goals and being better off financially. However, it can be difficult to concentrate, mean working outside of contracted hours to keep up, be exhausting and overwhelming. You may not feel able to take on a promotion or extra duties, look for or change to a new job. You could decide that staying, modifying what you are doing or leaving is the best choice for you.

Reducing hours, moving to a work-base nearer home, taking a sabbatical or having a period of unpaid leave might be alternatives to handing in your notice. If your employer has a human resources department, occupational health service or employee assistance programme, you could consider approaching them or a union for confidential advice.

YOUNG CARERS AND YOUNG ADULT CARERS

Under 18's who provide care are acknowledged as young carers, under 25's are known as a young adult carers. Your role of caring can mean you feel different from others, are isolated or miss out doing things your peers are.

If you are at school, college or university, staff should be able to listen and support you, making helpful adjustments such as permission to go home at lunchtimes or extending deadlines. Adult Social Care can provide support to reduce excessive caring, offering respite and support you to be able to stay in education.

Local young carer organisations are there to help you to cope with your role, typically offering emotional support, information, signposting, advocacy, health, safety and life skills training, activities, outings, breaks and groups with carers your own age who are in similar circumstances.

> **"It's nice having Granny living with us and I would like to learn more about her condition and how I can help her"** *Lucy, 10*

CARING FOR PEOPLE WITH PSP & CBD

As many symptoms can look like other neurological conditions and there are no simple tests or scans, PSP & CBD can be difficult to determine. Additionally, because the diseases are so rare, a lack of professional awareness about them is common. These factors mean delayed identification or misdiagnosis is frequent, causing confusion and frustration for all involved.

"I feel so passionately about PSP & CBD, and get frustrated that very little is known generally and within the NHS about these horrendous conditions" *Allison, 60*

The needs of people living with PSP or CBD can be as complex as the health and social care system can be to navigate. It may be difficult to understand what is happening or know what to prioritise focusing on. Difficulties with balance, movement, vision, cognition, speech and swallowing can develop over time, meaning many different types of staff and specialists may be involved at various points. Carers often report there is a huge amount of administration that goes with supporting their loved ones; from managing appointments to applying for resources to help, caring now and planning ahead.

"All the time I'm thinking, 'what's the next development' and being ready to organise or implement a change in my way of working or arranging support. I found it really helpful to explore who are the sources of help, and to call on them as required. It took some effort but is useful. Some sources of assistance can help more than others. It helps to identify which" *Bob, 78*

"Keep a book with all the key details about your loved one, e.g. NHS number, date of birth, GP surgery details, etc so it's always to hand when you need it. Keep a log of who you speak to within NHS, local authorities, and other organisations as it can get very confusing and complicated. It's also a useful record for future assessments and grant applications and so on" *Alison*

"We need time to adapt to changes and have a period of adjustment while working out how to deal with the next thing. It helps to be clear who we can go to – is there a single point of access, who can we go to for answers? We need things doing when they need doing, we can't always wait" *Margaret, 69*

There is a physicality to caring for someone experiencing loss of mobility and strength, having regular falls, and requiring assistance for moving or using a wheelchair. Alongside the emotional impact and life changes, it can be exhausting. Try not to cope on your own.

Help can come from many angles as well as unexpected quarters. Parkinson's and dementia services will often provide support, and due to PSP & CBD being long-term, life limiting conditions, palliative hospice care is available.

"As a carer for my wife for the last 6 years I would not have coped without the support from our local Hospice. Two days a week I take my wife in for the day. She is non-verbal and cannot do anything for herself as CBD has taken hold. I try not to feel guilty but it's hard!" *Barrie, 78*

"Being a carer can be challenging but also at the same time rewarding. The most satisfying aspect of caring, is being able to provide loving support to the best of your ability at a time which maybe frightening and frustrating for our loved one, who is experiencing changes to their ability to cope with everyday tasks.

"Developing personal skills such as patience, understanding and compassion all help when providing support to your loved one. Simply being there to reassure, to provide love, help and support when needed, I am sure helps them cope with the changes they are experiencing" *Paul, 76*

HOW CARERS WANT TO BE SUPPORTED

ASK ME

Ask me how I am

Ask me how I am coping

Ask me how I am *really* coping

A carer is still a person in their own right; they are not only a ‘role’ or superhuman. Carers want to be asked how they are too. Be mindful of the carer as well as the person receiving care. They may be talking about their challenges as a carer but that doesn’t mean they are looking for the situation to be fixed.

> Although I want to see friends, with the tiredness of caring I haven’t got the energy to socialise. *Margaret, 69*
>
> It’s hard not being able to chat with my loved one (with PSP) and share things as I normally would; our relationship has completely changed. *Ness, 45*
>
> We still want to be involved and carry on as normal a life as possible, and be the person we are, rather than be seen solely as a carer. *Diane, 64*
>
> People see me differently, they don’t come to me for help anymore and this used to be one of my roles, how I saw myself; being a listener and helping people. My identity has changed, I am not me anymore and that has been difficult to accept. *Maggie, 64*
>
> I want to know real life is still out there and be a part of it. *Ness, 45*

HOW COULD I HELP A CARER?

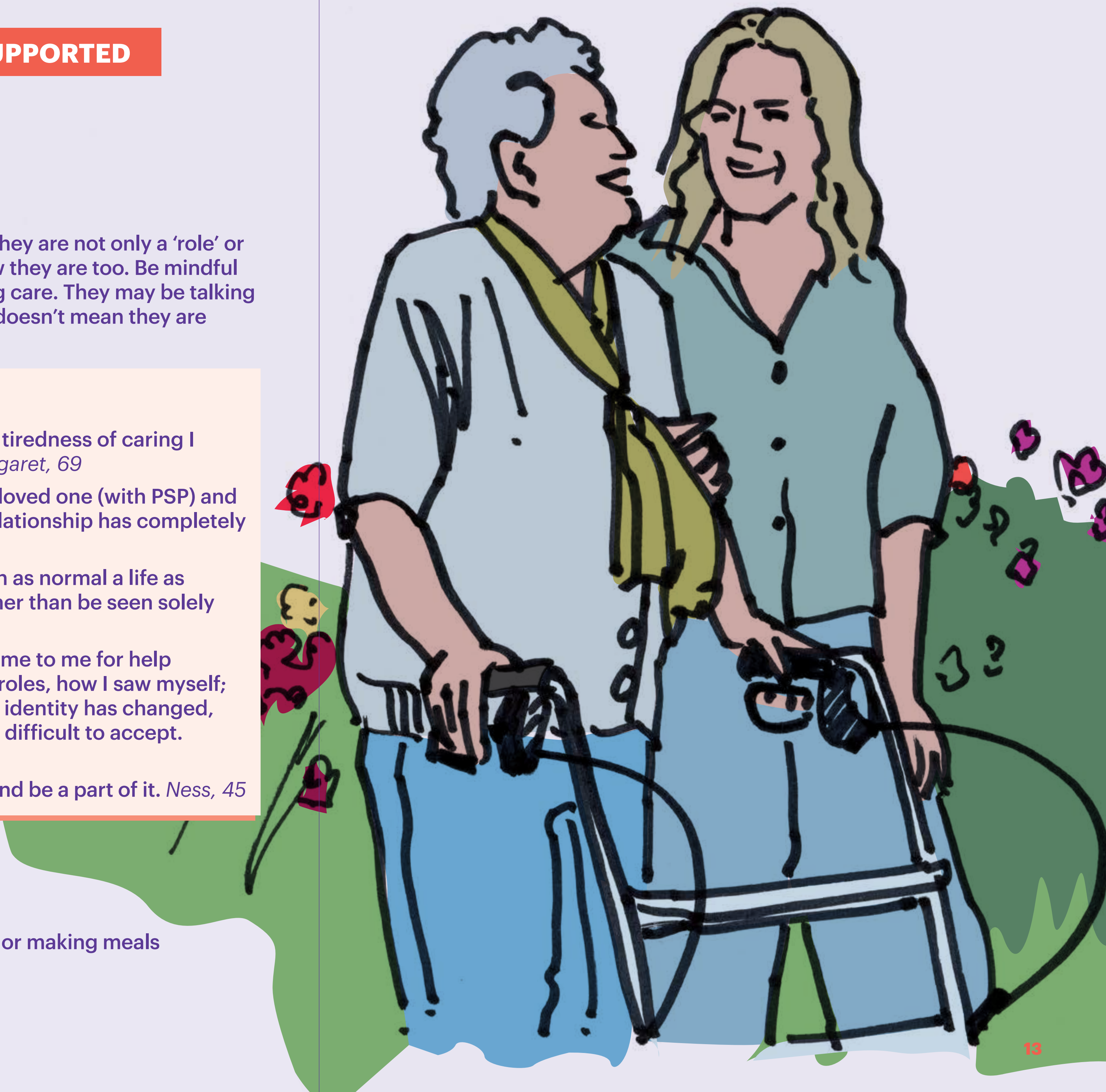
Openly acknowledge their role

Provide a genuinely listening ear

Offer practical help, like getting shopping or making meals

Give them breaks

Include them in normal life



PSPA SUPPORT

PSPA are committed to ensuring that family and unpaid carers of all ages who support people with PSP or CBD, have access to a range of support, networks and high-quality information. We also work to improve the quality of life for all affected through awareness-raising and research.

We offer to carers:

PSPA Helpline – Confidential telephone and email service open Monday to Friday 9am–9pm. Talk to your designated Helpline Care Navigator who can offer specialised information and support.

Publications – From booklets to factsheets, downloadable from the website or hard copies that can be posted via the Helpline. Some information is tailored for professionals and many carers find it useful to pass publications onto their GP, paid carers, health and social care staff or support organisations.

Online Carer Support Groups – Monthly daytime and evening groups, divided into regions across the UK and facilitated on zoom.

Young Adult Carer Support Group – Regular self-running peer support sessions online via Zoom and WhatsApp.

Health Unlocked – Our online forum provides the opportunity to share experiences and support each other with PSP and CBD-related challenges.

PSPA Support Groups – Regional Support Groups around the UK for those living with PSP or CBD, their carers and supporters.

PSPA Support Grants – Payments of up to £250 towards providing an item or service to help improve the quality of life for people living with or affected by PSP or CBD. Examples of grants given include counselling sessions, respite care, specialist transport costs, personal trainer sessions, and moving and handling aids.

Research – Free research conference days on the latest findings and newest initiatives in PSP & CBD. Support to access opportunities for you and your loved one to be involved in current studies.

Link Volunteer Service – One to one support to families in their region.

> **"Join the PSPA Health Unlocked forum and read the posts each week. There is no better source of advice and help about CBD & PSP"** *Richard, 61*

> **"As a result of the PSPA support groups and handouts, my husband and I have made a review of our wills, Power of Attorney and Living Wills with quite a lot of changes – thankfully before he may lose the ability to make decisions and sign"** *Hazel and Hugh, both 73*

OTHER CARER'S SUPPORT

Local authorities are required to ensure there will be an organisation dedicated to carers in your area. Carer organisations are a source of information, advice and activities, a way of connecting with other carers and receiving support. The majority also provide carer assessments (see pages 6–7).

Social prescribing link workers or coordinators are often connected to GP surgeries, and have detailed insight into what community support, activities and services are available.

Other charity and voluntary organisations based locally to you may have services you can also use as a carer or with your loved one. For example, befriending, counselling, transport, advocacy and groups. Searching online or going into your library can help you find out more.

National organisations such as Carers UK research and present statistics evidencing the overall picture for carers, providing guidance, a range of online and telephone-based services and connecting you to your local organisation.

The Carers Trust focuses on campaigning on the behalf of all unpaid carers, influencing policy and decision-makers for recognition, better support and legislation.

"It has been a huge learning curve and I found PSPA such a help as I navigated my way around the illness. One of the best pieces of advice was to get a nominated doctor, just one in the Practice who gets to know your partner and what PSP actually is. So many have never heard of the illness.

My doctors knew nothing about PSP, but I was able to give them the booklets provided by the charity. The booklets are so helpful and even yesterday in the Care Home one of the carers told me she found the pack I have given to them to be so helpful. She said she had never heard of PSP and had no idea about the behaviours involved" *Suzanne, 74*

HOME ENVIRONMENT

Our homes often show something of the essence of who we are, reflecting aspects of ourselves and our lives lived. We decorate and furbish in the way that suits us, and fill walls and rooms with things that we have accumulated through life, that we want or use. They are places where we have memories tied into the building and neighbourhood. Our home is our home and personal to us.

When PSP or CBD develops, it will be necessary to consider whether your loved one's home environment is going to accommodate the person's present and future needs; if it requires adapting, equipment installation, swapping existing room use or a potential move elsewhere. This can feel unsettling, be disruptive and feel intrusive to how we want things to be. Changing our surroundings can have a significant impact on us and provide ready reminders of what is different now.

If there are to be alterations, it can be useful to spend some time thinking about how you can keep things homely and familiar, and if you are living with your loved one, what do you need to retain for yourself.

You may have always enjoyed home decorating, DIY projects or reorganising, or having work undertaken could fill you with dread; either way get support, especially for major or specialist adaptations.

ADAPTING THE HOME

Setting up home facilities should enable greater independence and safety in relation to activities of daily living, meaning your loved one can stay in their home or continue to receive care there. Adaptations can be a great help and relief from the struggle or inability to do tasks, helping access different parts of the home or providing the ability to get out. They should be user-friendly and fit for the purpose of anyone providing care.

There are many things that can be done from stairlifts to ramps or door widening, installing wet rooms, non-slip flooring, through floor lifts, ceiling tracks for hoists or converting garages and conservatories. Talk to people in similar positions, being mindful that what one individual with PSP or CBD will require, may not be the same as another because the progression of the disease varies from person to person.

Discuss options, feasibility, grant availability and zero-rated VAT exemption with an occupational therapist from Adult Social Care; even if you are self-funding, advice should be forthcoming. Depending on the council, means-testing does not always apply. A trusted builder, architect or specialist company could also advise.

Modifying a home does not always have to be bound by what statutory services can provide but by what is possible. There can be more creative ways around problems than first appear.

Remap is a charity that helps disabled people of all ages to live more independent lives. They have a network of skilled volunteers who design and custom-make equipment free of charge, providing solutions to everyday problems when there is nothing commercially available. Their network of skilled volunteers responds to thousands of requests for help every year. An example of Remap's work includes a bespoke raised onto and off raised ramp onto and off from a balcony creating access for a wheelchair user in their flat.

PAID CARERS

Paid carers can provide a range of help with activities of daily life such as washing, dressing, toileting, medication, meals, shopping, companionship and sitting services. You may seek help as a private arrangement or care packages may be recommended and arranged by social workers or other professionals. You can request a list of approved care agencies from your local council.

There can be staffing shortages in some parts of the UK, meaning suitable trained carers could be hard to find and employ, whether you are going to be paying or the service is being provided. Seek advice from your nearby carer's organisation or Adult Social Care service, to ensure you have tried all avenues available in your area.

Having clear aims for receiving care helps everyone to know what the needs and expectations are. Decide what you would like care to include, when and how. Entrusting the care of your loved one to others can feel like a failure on your part, generating a sense of guilt, which, although a common response, has no basis and in no way takes away from your commitment to your loved one. Be prepared that it can require some time, for all involved, to get used to receiving care from someone else, having new people in your home, building relationships, mutual understanding and managing visits.

'THE RULE OF THUMB'

"My husband went into hospital and then a care home temporarily, because I felt I could no longer look after him safely at home, he was falling so frequently. I worked with various professionals to put a care package in place, which consisted of personal assistant (PA) cover from 08:00 to 20:00. On his return home, I became concerned there was no easy way that he could call us, if he needed to, as my husband can only speak in a quiet whisper. I felt very uneasy and unable to relax at all.

"I thought about whether I could learn anything from his time in the care home and decided to buy a call bell with several receivers. My husband wears it around his neck constantly now and is not afraid to press his bell whenever he wants something, no matter how big or small it is, which we've impressed on him to do. His PAs and I can now relax knowing that he can make it known if he needs us. I would be really lost if he didn't have his bell. I would suggest one for any non-verbal person. We now joke about living under the rule of thumb; because my husband does a thumbs up and down to indicate yes or no and presses his bell with his thumb. It's amazing what he still manages to control and get done through his humble thumb!" *Sue, 43*

CARE HOMES

Residential and nursing homes provide short or long-term 24-hour care and respite. The difference between residential and nursing homes is the level of support, with nursing homes available for complex needs and medical interventions.

As with having paid carers come into your home, it is a major adjustment to adapt to your loved one moving, whether that is from your shared home or their own. It can also trigger a strong sense of loss; even though your loved one is still around, give yourself time to get used to the change.

Always remember you are more than a visitor, your ongoing role as carer means you can still influence decision-making and care-planning. You are the holder of vital insights and information for staff about your loved one's history, likes, dislikes, approaches that work well, what you have tried before and what your loved one is communicating, to continue ensuring their comfort, safety and support.

"I now visit on a daily basis and provide care for my wife by giving her lunch as she is no longer capable of feeding herself. This means I feel that I can still provide help and at the same time taking some of the workload from the staff at the nursing home" *Paul, 76*

CARING AT THE CARE HOME

TOP TIPS

> Try out a few nursing homes for short stays first.
>
> Remember you will still remain a carer although your role will be different, being an advocate for your loved one.
>
> A move of your loved one to a nursing home does not have to be seen as giving up your role as carer. It may be more challenging than looking after your loved one at home.
>
> One benefit of your loved one choosing to live in a nursing home may be that there could be social contact with other residents with shared understanding of their condition and empathy with them. *Bill, 74*

HOW CAN I STILL BE INVOLVED?

Join in with care home events

Support at mealtimes, eat together

Bring in familiar items for the room from home

Get to know other residents, their carers and visitors

ACTIVITY IDEAS

Embark on a project to enhance the room

Listen to music

Go into the garden area

Encourage other people to visit

> Last year was my tenth year of being a carer to my husband who has PSP. Due to my own ill health, he was admitted to a nursing home. Life is now better for both of us. He has the care he needs 24/7 and I am now able to 'sit and stare'. Please be kind to yourself and know when PSP or CBD can defeat you. *Betty, 69*
>
> Continuity and a face which they recognise, I am sure goes a long way to reducing anxiety and stress for our loved one. *Paul, 76*

EMERGENCY PLANNING

Being prepared to respond to situations gives you the best chance of coping when there is an emergency and can provide greater peace of mind. There are several resources to help you do this, from schemes and systems to services. You may also want to include other family, friends or neighbours in your contingency and share or agree plans with them in advance.

Carers Emergency Cards – Provided by national or local carer organisations, councils or charities, Carer Emergency Cards let others know you are responsible for looking after somebody in case something happens to you. Many include a phone number to a 24-hour call centre who hold your plan and will initiate your instructions. The majority of these services are free, check your local arrangements to find out your options.

Key Safes – Key safes are wall-mounted boxes to put outside the front of your home. Here you place a set of door keys inside to be accessed using a keypad and code. This enables trusted people to be able to get into your home. Key safes are readily available, chose one that is police- approved secure.

Telecare – Telecare is the use of technology to support people to live with as much independence as possible. The most common aids are personal alarms, which are worn and activated to indicate help is needed, some types include falls detection capability. A call or message is sent to a call centre or predetermined numbers to let them know there could be a problem. Room monitors help to hear individuals around your home. Sensor pads alert if someone is getting up or has gone into a certain area, they are also used to prompt a person to a doorbell, phone ringing or danger.

Lions Fridge Scheme – Six million people across the UK use the free Lions 'Message in a Bottle' to keep health information on diagnoses, medication, allergies, disabilities and other details in their fridge for emergency services to find if they visit. Stickers are provided to put onto the outside of a fridge, and personnel are trained to know to look for this.

DEALING WITH FALLS

A common concern for carers is how to help their loved one up safely after a fall without hurting themselves. Always ring 999 if there is injury or concern. However, many places have alternative local support like Community 1st Responders to come out and assist where an ambulance is not needed. There are also equipment options to keep at home, such as slide sheets to move people into easier positions to get up from, and inflatable lifting cushions and seats. Ask an occupational therapist for more information, what can be provided and for training on how to use any kit.

GETTING OUT

It is important to keep getting outdoors when you can, not only does it give you vitamin D from the sun and fresh air but keeps you feeling part of the wider world around you. Here are some resources to help you with where to go and how.

AccessAble – Reviews of over 10,000 venues and locations in the UK and Ireland. Use their website to check out disabled access, facilities and wheelchair-friendly venues before you go.

The Rough Guide to Accessible Britain – A collaboration between Motorbility and the Rough Guide publishing group. This book covers everything from scenic drives to galleries, museums, gardens and ideas for day trips and breaks.

Ambulance Wish Foundation UK – Provides free, highly specialist transport to make getting to venues accessible for all, granting wishes for those with advanced needs, including those who are bed-bound.

Radar Key – Access over 10,000 disabled toilets across the UK independently with your own RADAR key, also called the 'National Key Scheme' (NKS). Order one from your local authority.

Carers Discount Cards – Nationally and locally, there are various discount schemes for carers, some of which you pay for, others that are free. The cards work as providing identification to receive reduced pricing for places of interest, entertainment, leisure, retail, events, transport, health and wellbeing activities. There are versions doubling-up with emergency contact details for you if anything were to happen, these can also be obtained separately see page 22.

Blue Badge – Parking for people with disabilities enables closer parking to where you are going. You can hold a Blue Badge if you are the driver or the passenger parking with less restrictions in your local area, in designated disabled spaces, on yellow lines for up to three hours or in pay and display metered areas. You will need to complete a form for your local council, providing proof of disability parking for free.

HOLIDAYS

The ability to go on holiday might seem far-fetched, the thought of leaving your home and the practicalities it could involve, may seem insurmountable. It can also be difficult to cope with seeing others getting on with their own lives and enjoying trips. However, a diagnosis of PSP or CBD does not mean you never go away again, holidays are an option. It takes more planning, but there are many companies who can help to make things work for you and yours. PSPA review travel insurance yearly; contact our Helpline for the latest on who will provide cover for trips with your loved one.

> **"In the earlier to mid stages, take as many holidays as you can afford. Seize the day!"** *Richard, 61*

WHERE TO STAY?

From purpose-built centres, days out and adventures abroad with personal care support, cruises providing accessible floating hotel experiences, adapted cottages for hire, holiday park accessible caravans and lodges, with walk-in and wheel-in showers, electric beds and level access, there is a great deal of choice. The Disability Holidays Guide advertises accessible holidays from worldwide travel companies to small family run businesses.

TOP TWELVE ITEMS TO PACK

Waterproof bed sheets – reassuring and secure.

Portable commode – folding and lightweight, for a discreet corner.

Portable shower seat – helpful if not included in wet room.

Pull-up pants – more expensive than pads, but often more convenient for travelling.

Continence aids – conveen sheaths and leg bags, or shewees can bypass the need to use small train or plane toilets, or to keep getting up on a journey.

Medication – ensure you have enough, try using a pill box for ease.

Sun protection – some medications make skin more sensitive to the rays, pack high factor sun cream to avoid this. Sprays and roll-on versions can be easier to put on.

Adaptive kit – from small things such as drinking straws to large items like pressure cushions, make a list of what you use day to day, and tick off when you pack.

Paperwork – not just your tickets, take important telephone numbers, any key documentation you may need if medical intervention is required, plus any carer cards for discounts and emergencies.

Passenger assistance – organise this with airports, train, ferry companies when you book. They will be able to greet you and support with terminus transport, waiting lounges, going through barriers, getting on and off, moving luggage and so on.

Ready meals – have a break from cooking and take a range of favourites.

Supermarket delivery – pre-order food and toiletries, timed to arrive on your first day.

With thanks to intrepid explorers Keith and Chris.

TRANSPORT

TRANSPORT TO BORROW

FOR HIRE

The British Red Cross offers safe and reliable manual wheelchairs whether you're looking for self-propelled, transit or bariatric (wider seating, higher weight capacity) wheelchairs. Available in all sizes, with fitted footrests as standard and free accessories such as leg elevators, cushions and supports to improve comfort. The minimum hire period is for a week. There is a basic cost, which includes any additional accessories. Add door to door delivery and collection for an extra fee.

Shopmobility UK coordinates all the local Shopmobility services, providing power chairs, wheelchairs and mobility scooters to hire at low cost, discretionary donation or for free.

TO RIDE

Age UK and the Royal Voluntary Service provide door to door community and patient services for older people to support maintaining independence.

Dial-a-Ride schemes run in different parts of the country from Edinburgh to Surrey, Denbighshire to Bristol, East Lancashire and London to name a few. Please search the internet for Dial-a-Ride and your area to see if this is available for you.

Taxicard offer reduced payment schemes for disabled residents in some cities. For example, those living in London Boroughs can apply for Taxicard through the local council.

TRANSPORT TO BUY

If you are looking to purchase privately, choose a sales team with expert support who are approved assessors. Once you know a good fit for your loved one and yourself, look out for opportunities to buy pre-used. Many of the established and well-known specialist companies are renowned for their clearance sales and high levels of customer care. Some consumer comparison sites rate different vehicles, wheelchairs and power scooters and advise on purchasing. However, there is nothing like trying out a variety of options, before you buy.

FINANCIAL SUPPORT

With Motability, exchange your qualifying mobility allowance for a brand-new car, Wheelchair Accessible Vehicle (WAV), scooter or powered wheelchair, so you can enjoy more freedom and independence.

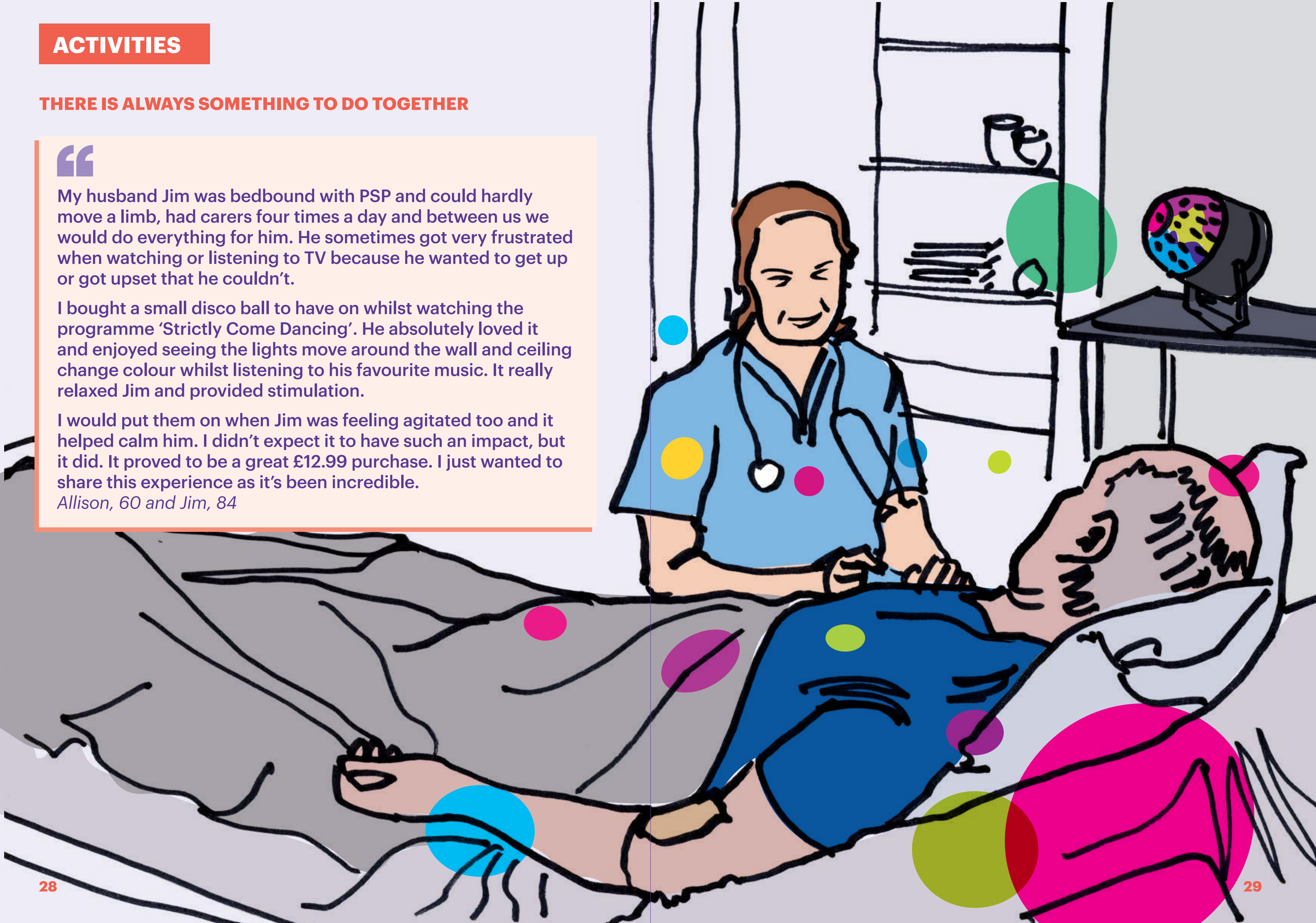
Those eligible should be receiving any of the following: higher or enhanced rate of the mobility part of either Personal Independence Payment (PIP), Disability Living Allowance or the Social Security Scotland Adult Disability Payment; the Armed Forces Independence Payment; or the Veterans UK War Pensioners' Mobility Supplement.

> **"My wife needed to go up and down to hospital regularly, and transport was going to cost a fortune, so I thought it would be cheaper to buy an old ambulance. There was no need for any modifications as it had the hoist in place, and I had the hydraulics checked out, which were fine. It was a bit bigger than we needed but we used it for three to four years and it was well worth it. Just ensure you have got the parking space for it!"** *Robin Wylde*

ACTIVITIES

THERE IS ALWAYS SOMETHING TO DO TOGETHER

> My husband Jim was bedbound with PSP and could hardly move a limb, had carers four times a day and between us we would do everything for him. He sometimes got very frustrated when watching or listening to TV because he wanted to get up or got upset that he couldn't.
>
> I bought a small disco ball to have on whilst watching the programme 'Strictly Come Dancing'. He absolutely loved it and enjoyed seeing the lights move around the wall and ceiling change colour whilst listening to his favourite music. It really relaxed Jim and provided stimulation.
>
> I would put them on when Jim was feeling agitated too and it helped calm him. I didn't expect it to have such an impact, but it did. It proved to be a great £12.99 purchase. I just wanted to share this experience as it's been incredible.
>
> *Allison, 60 and Jim, 84*



FINANCE AND BENEFITS

You and your loved one will be entitled to monetary support. The amounts and types vary depending on age, circumstances and needs. Some benefits are means-tested and others are not.

You may feel uncomfortable asking for or receiving help, but the cost of care for people with PSP or CBD can be extremely high and monies are designated to be used by those with long-term, life-limiting conditions.

Finance can range from carer's allowance, carer's credit, personal independence payments, carer's attendance allowance, tax credits, housing benefit, zero-rated VAT exemption, council tax reductions, respite costs, disabled facilities grants, to Motability for accessible vehicles, employment support allowance and statutory sick pay. PSPA produces a *General Benefits & Entitlement* fact sheet for basic guidance.

If you would more information on the benefits you may be entitled to please contact the PSPA Helpline. Your PSPA Helpline Care Navigator will be able to refer you to the Department of Work and Pensions Visiting Service.

Further sources of assistance come in the form of prescribed equipment such as continence aids, perching stools and hospital beds; charitable organisation support groups; exercise sessions; trips; and low cost or free counselling. Carers leave may be available for those working from their employer. Voluntary assisted transport disabled and carers discounts and exemptions – from sports centres to public transport concessions, blue badge schemes and entry fees. Charities that support those retired from their vocation such as veterans. .

VAT exemption on goods need to be for sole use of a person with difficulties to be eligible and determined as 'zero rated'. Items include adapted motor vehicles, mobility scooters, wheelchairs, specialist footwear and home modifications. There is a UK VAT Disabled Relief Helpline to help answer questions.

> **"I get 4–5 hours of respite care a week from a referral made by the local carers association and obtained through the council. I now have that time for myself. But it's so easy to lose your identity as a carer because caring becomes everything and it could end up defining you as a person. You need to try and step back, remember who you are so that you can move forward when the time comes in the future"** *Marcus, 63*

NHS CONTINUING HEALTHCARE FUNDING (CHC)

NHS Continuing Healthcare is the name given to a package of care that is arranged and solely funded by the NHS for individuals who are not in hospital, but who have complex, ongoing healthcare needs. It is only available for those that meet specific eligibility criteria and are considered to have a 'primary health need'. Not everyone with a disability or a long-term condition (such as PSP & CBD) will be eligible, as the assessment is based on the nature, complexity, unpredictability and intensity of identified health needs, rather than a specific diagnosis.

NHS Continuing Healthcare can be provided in any setting, including a person's home, or a care home. If at home, then it will cover the costs of assessed health and personal care needs. If you live in a care home then NHS Continuing Healthcare covers the cost of assessed health and personal care needs, as well as accommodation and board costs.

PSPA has produced a detailed factsheet on *NHS Continuing Healthcare* and the organisation Beacon Continuing Healthcare have support for families navigating the system.

LEGAL ARRANGEMENTS

Managing your affairs today can be difficult enough, without having to also think about the future when caring for someone with PSP or CBD. However, life ahead can be made easier by having put in place key legal arrangements early on. As a carer, you are likely to be advocating on behalf of your loved one, so knowing their wishes from the beginning is important for you and your family. It may also give you a sense of being more in control and ready, having the legal documentation required for times when medical decisions might need to be made with little notice.

> **"You have to be really proactive, and that's hard work when you're trying to care for someone. You can't just sit there and think, oh crikey. Nothing lands in your lap, and you have to get things put in place relatively quickly and make a raft of decisions for that person as well as caring"** *Marcus, 63*

POWER OF ATTORNEY

Power of attorney is a legal document that allows you to make decisions on behalf of another. Power of attorney can only be set-up while the person still can weigh up information and make decisions for themself, known as having 'mental capacity'.

There are two forms of power of attorney, Ordinary Power of Attorney (OPA) for temporary arrangements, and Lasting Power of Attorney (LPA), which is ongoing and has no expiry date. The most common is Lasting Power of Attorney, which has two types for England and Wales - Health & Welfare (called 'Welfare' in Scotland, this is not available in Northern Ireland), and Property & Financial Affairs (known as 'Continuing' in Scotland or 'Enduring Power of Attorney' in Northern Ireland). In Scotland, having both aspects is referred to as Combined Power of Attorney.

Health & Welfare or Welfare LPA's cover aspects like medical interventions, daily routines, respite and moving into a care home. Property & Financial Affairs LPA's look at directives for managing bills, collecting pension or benefits, looking after accounts and selling property.

LIVING WILLS, ADVANCED DIRECTIVES AND ADVANCED DECISIONS

These terms are used interchangeably, and all mean the same thing: to describe your wishes for when you may not be able to communicate these.

PSPA provides an *Advanced Decision Guide for those with PSP or CBD* with a large amount of detail to support you. This is designed to be used in conjunction with the forms from Compassion in Dying which come with the PSPA pack.

KEY ASPECTS

PSPA has specific information on topics such as Tube Feeding to help you explore options and other sensitive issues like Brain Donation for Research to give you details on what else you may wish to consider in advance.

Knowing whether your loved one would wish to be resuscitated if they had a cardiac arrest, is another important element. If they do not, then a Do Not Resuscitate (DNACPR) order can be put in place. The NHS website explores the topic, what it entails and legal requirements to put this in place.

MAKING A WILL

A will states what you want to happen to your possessions and money when you have died. You can write a will yourself if you carefully follow rules (the government provides guidance), or make one through a solicitor.

To help you make or update your will PSPA have partnered with a company called Farewill who are able to offer a free will scheme. For more information contact PSPA or see page 51 of this guide for website details.

DEALING WITH DIFFICULT CONVERSATIONS

Carers often need to raise sensitive, highly personal matters or will have different viewpoints about care than their loved one, wider family, friends or professional staff. You might be dealing with day-to-day care or complex issues that are happening now or you are considering for the future, such as working through advanced planning.

WITH EACH OTHER

Having a diagnosis of PSP or CBD, means communication can be increasingly compromised. Cognitive impairment may develop, including difficulty for the person to conceptualise all sides of an issue; there could be impulsivity; confusion; yes and no might become mixed up or not retain their meaning, and decision-making may be affected. The progression of the disease is not predictable in speed or how it manifests, so early conversations are advisable.

> **"It can get increasingly harder to communicate with your loved one until one day it is almost impossible. So do all the talking while you can"** *Richard, 61*

WITH FAMILY AND FRIENDS

People around us can respond in many ways to PSP & CBD impacting your life and that of your loved one. They may be a great support or not know what to say and back off. They can be well-meaning and want to fix everything. Individuals can have very strong opinions or remain quiet, and there may not be a consensus on what decisions are to be made or by whom. Pre-existing family issues can be exacerbated by the change in health of your loved one or bring people closer together.

WITH PROFESSIONALS

At PSPA we have long recognised the need to provide advocacy and information to those caring for people with PSP or CBD. Many professionals including the health and social care community are unfamiliar with these diseases and will not know what may be required and when.

> **"With hindsight we wished we had more information about palliative care as although Dad had an advanced care plan, we hadn't really had any contact with the local hospice to know what support they could offer. So when we were asked about what we wanted when Dad became very unwell at the end of his life, we didn't really know what the options were. It might also have been good to know that we could have been referred to the hospital palliative care team before Dad's final days and they would have had these conversations with us and given us support to prepare for his end of life"** *Jen, 44*

GETTING READY TO TALK

Before you start, plan what you want to say and think about what you hope the outcome will be from raising the issue:

Why – What is the purpose of your conversation? What are you aiming to achieve from it?

When – Is it a good time? When won't you be rushed or interrupted? What suits you? When are you at your best? When will you feel most ready to address this? Do you need longer to prepare? Do you need to get this out of the way or prevent something escalating?

Where – Is it the right place? Face to face, over the phone, emailing or internet meeting? Would you prefer going to the person or for them to come to you?

How – How are you going to broach your concern/point/issue? Try writing down your questions or points in advance. Draft something, then leave it for a while. When you go back are you happy this is what you want to say? Will you have the privacy you would like? You are not responsible for others' reactions but how might you deal with the way they respond, e.g. politely end the conversation, say perhaps they need time to think, arrange to speak again when they are ready to, ask for a response back by a particular date?

Who – Does it have to be you bringing this up? Is there another person who could on your behalf? Do you have anyone you can talk to about what you want to say before, or ask to check a draft email or letter? Remember you can always call the PSPA Helpline on 0300 0110 122 to run things past one of our Helpline Care Navigators or join our online community HealthUnlocked via the PSPA website and post your thoughts there.

CONVERSATION OPENERS

Your beginning sets the tone for the rest of the conversation but sometimes starting off is the hardest part. Try using one of these phrases:

"I would like to talk to you about something sensitive/that is difficult to say/might be hard for you to hear/might take me a while to get out/I'm not sure how to say..."

"We both want the best for X, let's work out how we can help X together..."

"I am not sure I understand this decision, please can you explain the reason why..."

"I have noticed a change that I am finding challenging to get used to..."

APPROACHES

Be straightforward and use facts, present your information neutrally. This is especially important when your topic is emotive or might generate a defensive response. For instance, "I'm unhappy with the service as our last two appointments have been cancelled".

If you don't understand what someone is saying, for example if there is a lot of jargon being used or you can't see what point is being made, ask if they can say it in a different way or write it to you.

Acknowledge that your own feelings might affect how you communicate; even if you tend to be calm, frustration can show through our body language, tone of voice, eye contact and gestures.

Try to be clear about the exact purpose of the conversation and if you want an outcome, what it is. Be curious, ask follow-up questions if you haven't got a satisfactory response or answer.

ENDING WELL

You could ask the person to sum up what they have said or agreed to do, verbally or in writing. If things aren't going well or you don't want to continue the conversation, suggest you both take a break and set another time to talk again.

Give yourself time to reflect on how the conversation went. Trust your experience and knowledge as a carer. Did you say everything you wanted to, does there need to be another talk, are you satisfied with how things were left? Consider any further steps you might want to take.

Challenging conversations can be an opportunity to grow in confidence, perhaps in ways we didn't think applied to us. Carers often say they have become more assertive as they have needed to speak on behalf of their loved one and themselves in new ways.

SPEECH & LANGUAGE ASSISTANCE

Speech & Language Therapists (SALT) assess and support those having difficulties speaking, swallowing, eating and drinking. If your loved one is struggling to communicate, they may suggest helpful ideas or adaptations for you both to use.

PSPA have a partnership with an organisation called, 'SpeakUnique' who provide voice banking for people living with PSP or CBD depending on their speech needs. Aiming to create a personalised synthetic replica, sounding as close to the individual's natural voice as possible, SpeakUnique use recordings and personal details, such as regional accent and age, to build, repair or design a voice to be used with technology. Funding for voice banking via SpeakUnique can be applied for alongside a PSPA Support Grant, please see our website for details.

EMOTIONAL HEALTH FOR CARERS

The role carers give is often taken for granted, yet it is one of the most significant and invaluable things we can do. Many juggle education or work, give jobs up altogether or completely change their school, career, family, living arrangements or retirement plans to support.

Carers UK statistics show people providing high levels of care are twice as likely to develop health issues, with 72% of carers saying they had suffered mental ill health because of caring. Caring is a great service to another, it is kindness, duty of care, commitment, selflessness and love, but it can also be very hard on the carer.

> **“It is difficult to hear from a consultant that the person you love and cherish has a limited time on the planet, it hits you in the pit of your stomach very hard... some days I feel like I’m coping and other days I feel like I’ve had enough. It builds up, you fall, then have to pick yourself up and carry on”** *Marcus, 63*

FEELINGS

We all have the same range of emotions, and you may feel any number of different combinations, which change over time with caring – fear or anger, sadness or joy, acceptance or disgust, love or loathing, gratitude or thanklessness, guilt or pride, surprise or anticipation. Whether you are overwhelmed or coping, there are no rights or wrongs.

Take a breath to notice how you are, to acknowledge your feelings and decide if you need to do anything with them right now or let them be. Everyone is different and it is always better to ask how a carer might be feeling and what they mean, than to make assumptions.

> **“No one can fully understand what a carer’s life is like unless they have experienced it. I do not feel guilt. I do not feel that I have failed my wife. The facts are that at home I cared for my wife 24 hours a day with little help. I dealt with the most personal of her care needs. We are now in year 12 of her living with CBD.**

> **“The fact is also that my role now as a carer while my wife is in a nursing home is far more challenging and demanding than it ever was while she was living at home. That was easy in comparison. So, no I do not feel guilty or that I have failed my wife. I feel that it showed bravery on my part to accept my wife’s decision that the time had come for her to move into a nursing home”** *Bill, 74*

GETTING HELP

As a registered carer (see page 5) your GP should be looking for signs of the impact of caring on your health. It is not always easy to tell if you are unwell within the context of the day-to-day stresses that can occur from caring. If you are experiencing symptoms of persistent anxiety, sadness, low mood, despair, sleeplessness, fatigue, intrusive thoughts, panic, changes to appetite, apathy, agitation or poor concentration, see your GP. It may be you just need one thing to be different to tip the balance back to manageable, or you could receive more comprehensive help for you and your circumstances.

Carer counselling can be provided via telephone, online or through in-person support. You can request this through the local carer organisation or ask your GP to refer you. There are also some specialist talking therapies for those dealing with rare conditions.

Many find sharing what is happening with a trusted person invaluable. The PSPA Helpline is available and staffed by those who understand PSP, CBD and caring; please do telephone or email if you would like to, it is what the service is there for.

> **“During my darkest times I phoned the PSPA Helpline who are there to listen, and many times I just cried. They are wonderful, calm and empathetic. It just gave me an opportunity to talk to someone who understood”** *Suzanne, 74*

OUR EMOTIONAL WELLBEING

> “
>
> We’re grieving over our relationship and what we’re losing, we need time to express that grief. Sometimes it can all come out over a small thing, like putting out the rubbish, not just the big decisions. *Diane, 64 and Maggie, 64 in conversation*
>
> The spark that drew my wife and I together is still there deep down. Don’t lose it and above all laugh together when you can. *Marcus, 63*
>
> Realise that changes to your loved one’s mood and speech are a result of their condition, which may progress and change, and that they are unaware and it’s beyond their control. Don’t take it personally. *Paul, 76*

FIVE WAYS TO WELLBEING

Connect – with others, allow support, build your sense of belonging

Get Active – to lift mood, reduce stress and help you sleep

Take Notice – savour moments and the world around you, the little things matter

Learn – something new, set a small goal, learn a new word, way or wisdom

Give – thanks and kindness, have a listening ear for another carer

PHYSICAL HEALTH FOR CARERS

When you are caring for others, it can be hard to care for yourself too. With limited time, it can also feel difficult to know what to prioritise from all the wellbeing advice. Keep it simple, work around your levels of ability and energy as they fluctuate each day.

MOVING

It is not only formal exercise, but every movement that counts. Getting up regularly at home, using stairs, taking the dog out, gardening, carrying and putting away shopping are all activities that help to preserve our health. As a carer, you may be doing more or less than you used to or could have swapped some physical tasks for others, for example, helping with washing and dressing, instead of playing badminton.

You might go out to a sports club, gym, pool or class. At home, try using DVDs, games consoles (such as a Wii Fit), join a live group or use online videos. Many exercise options are available on the internet; from simple chair-based stretching to all out dance moves and vary from a few minutes to a full hour. Make sure what you try is safe, run by a qualified instructor and that your GP would approve.

The UK Chief Medical Officer recommends 150 minutes of moderate or 75 minutes of vigorous activity per week. However, the physical, emotional and mental requirements of caring and having more organising to do can be very tiring and it is important to honour your limits. Support such as making use of paid carers, using moving and handling equipment, and following good guidance for pushing wheelchairs can all help. If your loved one has fallen, get assistance from others so you are not putting yourself at risk of injury. Try to find a balance between being active and resting where possible.

ENERGY CONSERVATION

Build simple changes to make the best use of your strength, effort and time, with less strain on your body; reducing the fatigue and stress that is often associated with caring.

Pacing – going at the right speed with the amount of energy you have to spend, reserving energy for the activities you most want or need to do. Take cues from your body and listen to yourself – our energy is not just physical but mental and emotional too. Slowing down everything from our walking pace, work rate, talking and thinking can save us a great deal of unnecessary exertion.

Prioritising – Decide what you have to do and what can wait for another time. Will it really matter if the housework isn't done today?

Planning – Be realistic about what you can achieve. Try to take pressure off yourself, decide not to waste energy on the things you can't change. Get organised, gather everything together that you will need to complete a task before you begin. Break activities down into shorter, more manageable parts and spread them over a longer period. You will still achieve what you want to do but without having the pressure of having to do it all in one go. Plan frequent rest periods, even a few minutes can help us catch our breath, collect our thoughts and carry on more refreshed.

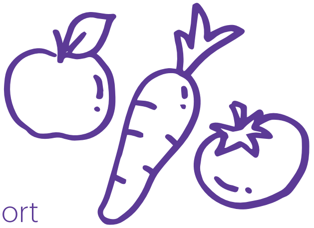
Positioning – Sit down instead of standing to do activities like domestic chores, where possible. For example, perch on a stool to chop vegetables or sort laundry sat in a chair.

Posture – Sitting and standing correctly helps us breathe more easily, taking pressure off joints and muscles. It allows our bodies to work less hard, enables better circulation and is a means to conserve energy. Think before you move to avoid twisting round, overreaching or leaning forwards without bending your knees. Check wheelchair handles are the right height for you to avoid hunching over whilst pushing. You should be able to keep your shoulders back and aligned, without sticking your chest or bottom out, with your 'push' power coming from your legs.

People – Ask for practical help, talk about how things are for you with others and what support you need to create physical breaks for you to rest.

> **"A carer has to stay fit in body and mind. I get to the gym weekly and go out for a couple of mornings' sport each week, supported by people who come in to take over. I know not everyone would manage this but a positive attitude towards it helps"** *Bob, 78*

EATING WELL



Having nourishing, nutritious food helps your body function effectively, giving you energy, enabling you to move more, sleep well and have the focus to do what you need to. It can also support your emotional wellbeing through your brain chemistry and the hormones released.

'Good mood food' is the positive relationship between what we eat and how we feel, with many ideas and recipes in books and online. These are items, ingredients or dishes that are designed to help us feel better in ourselves, give great long-lasting fuel without the experience of sluggishness, maintaining our immune system to fight off bugs and bacteria, and helping us to feel brighter.

General advice is to:

Eat regularly – Keep your blood sugar level consistent and energy up. Have healthy snacks of a mixture of protein and carbohydrate, for example, peanut butter, apple and oatcakes, ready to pick up when you need to.

Stay hydrated – It is easy to forget to drink when you are busy or concentrating on others.

Manage your caffeine – Find the level that works best for you. For some, too much is problematic, for others it is what helps them to get through the day and doesn't have any adverse impact.

Eat the right fats – Especially important for brain function and joint care.

Get enough protein – Important for slower release energy and helping your body repair itself.

Eat wholefoods – These are natural ingredients and contain more nutrients than processed food.

Have your 5 a day – Fruit and vegetables contain high levels of many essential vitamins and minerals.

Slow down – Make sure you taste your food and enjoy what you eat.

Have a bit of what you fancy – Enjoying what you want in the spirit of 'everything in moderation', to savour something for a moment or to get a little more sweetness into life.

SLEEP

Sleep helps us rest but it also restores our bodies, building and repairing tissue, and supporting the immune system we need to stay healthy. Reports on the connection between mental health and rest, suggest that sleep is as important as oxygen, food and water. Caring can seriously affect our ability and opportunity to sleep, and our capacity to function well during the day.

What can help carers?

Use adaptive equipment – If you think you are sleeping too lightly while listening out, or worried you may sleep too heavily to hear the person you care for, you could try using sensor mats that are placed under the pillow or on the floor and vibrate, or plug-in monitors to alert you to if your loved one has got up.

Get GP or specialist service advice – If your loved one is having difficulties with frequent toilet trips, incontinence, anxiety or loss of day/night routine. There may be strategies or medical intervention that could help.

Shut out light – With blackout blinds or curtains that cover the whole window and are flush to the frame and walls. On waking, step outside for a few minutes into the morning light to help prompt and regulate your brain's circadian rhythm that it is time to be awake.

Adjust technology – Blue light from devices causes us to be more alert, supressing melatonin and disrupting circadian rhythms. Have a break from mobiles, laptops, tablets and computers. Or if you are using a screen right up before sleeping, for example, you may read with a Kindle, play games on a phone or text people, try switching to night-light friendly settings to help your brain unwind and be readier to sleep. This could be called 'blue shade', 'night shift', 'bedtime' or 'dark mode' or similar in your settings.

Wind-down before bedtime – Whether it is with a hot drink, doing a crossword, reading, listening to music, meditating or praying, putting your worries out of your mind and onto paper, or having a warm bath.

Catch-up – If you can, nap in the daytime. Research shows a sleep of anywhere up to 50 minutes, between 1 and 4pm shouldn't disrupt your night's rest.

SOCIAL AND RELATIONAL HEALTH FOR CARERS

Caring can be an isolating or lonely experience. PSP & CBD may produce changes in your loved one's abilities to process what is happening and to express themselves, whilst caring adds a different dimension to relationships. Our wider networks can alter too from how we spend time, when we can see others and what we can do.

"Our roles can reverse, my husband always cared for me but now I have to drive on motorways" *Diane, 64*

PSP & CBD CHANGES AND RELATIONSHIPS

Relationships can become more strained from the stress of daily life with PSP & CBD. Changes may occur in a person with PSP or CBD, making communication more challenging. These symptoms could include reduced speech; posture affecting body language; inability to look up or down and a lower blink rate altering levels of eye contact; motivation impacting as apathy; impulsivity showing as risk-taking, mental rigidity; difficulty finding words; poor concentration; loss of concern for others; memory deficits or words not carrying the same meaning anymore. It may help to be clear these result from the condition and are not a breakdown in relationship.

Do whatever helps you to deal with this: go into another room, take deep breaths, count to ten, distract yourself, put on music, write it out. Be in touch with people outside your home even if just by phone, email or messages. Talk to someone trusted about how you feel. PSPA's publications give strategies to manage each aspect of cognitive and behavioural change. Adversity can also draw people together in new ways, being around each other more, seeing new facets and deepening bonds.

"My husband's personality has changed in that he gets the giggles" *Christine, 70*

"PSP doesn't always affect cognitive abilities. Although Dad's speech is no longer very good, he can still tell you all the gossip from the nursing home!" *Alison*

CARER BREAKS

Day care, sitting services, befriending, breaks given by friends and family, cover from visiting, live-in paid carers and short residential or nursing home stays are all forms of respite. Carer associations and social prescribing link workers give information on what is available to you locally, whilst Adult Social Care would undertake both a carer assessment for you and a needs assessment for your loved one to see what the best fit for any funded support might be.

WHAT TO DO WITH YOUR RESPITE

Some need no encouragement, others will just want to sleep, here are some ideas for successful a respite break.

"Last year, I received two-weeks respite from Continuing Health Care, which paid for Anne's accommodation. It took a couple of months to organise what we would be doing and 'planning' was the big word both for my wife, and for me. I organised and paid for specialist transport, and Anne went to a nursing home she had stayed at before where the carers already knew her.

"I packed everything in I wanted to starting with some local carers association activities, walking in the woods and a painting session I wouldn't usually be able to go to. I visited the Morgan Car Factory and after had a meal with my brother and his wife. I spent the weekend in Manchester with my son and his partner, going to RHS Bridgewater and Yorkshire Sculpture Park, meeting more family.

"I then went to Plymouth to see the 'Saltlines' show; poetry set to music, a collaboration with Raynor Winn, author of 'The Salt Path' and the group, Gigspanner. I got my copy of her book signed. Her husband Moth has CBD like Anne. I finished my round trip with a visit to Lyme Regis and went back to my namesake restaurant, 'Robin Wylde', which I had been at for the opening 24 months earlier. I gave the owner a 2nd year birthday card" *Robin Wylde*

ACTIVITIES

IDEAS FOR CARERS TO ENJOY WITH LOVED ONES

Indoor gardening – Bring life from the outside in, arrange cut flowers, grow herbs, get some pot plants, make an indoor 'border' or mini rockery on a tray. Preserve your flowers by pressing between pieces of newspaper in heavy books.

Music – This can act as a social mediator when language or voice is diminished. Change the mood or create atmosphere, distract and reduce stress. Create playlists or a favourite top ten, use energising music to help wake-up in the morning or before an appointment and winding-down music in the evening.

Sport – Keep following a beloved team or competition. Watch and learn about something you haven't seen before; weightlifting, curling, sumo wrestling, slalom skiing, bobsleigh, diving, ice hockey, snooker, table tennis or basketball.

Food – Do some 'cold cookery': mix ingredients to make no-cook fridge sweets. Choose menus, have a themed meal, try fruit you've never eaten before. Have a taster session where you rate something; chocolate bars, juices, pies and decide the winner on look and flavour.

CELEBRATIONS AND SPECIAL DAYS

Pass the Parcel using easy to tear tissue paper

Face time far-off family and friends

Light a candle of remembrance

Go through photographs or footage

Play music with memories

Decorate cakes for the occasion

CARER PEARLS OF WISDOM

“We have good days and not so good days… never a bad day”
Teresa

“What will happen in the future is for the future. It’s the here and now we have to cope with”
Friend of Bill, 74

“Take advice and accept support”
Paul, 76

“Get as much support as you can. The PSPA Helpline have been really useful for pointing out what benefits to apply for and advising about getting support like a cleaner and gardener in to help my parents. We also got a tea trolley, which helps them push drinks and meals from the kitchen to the lounge or dining room, and chair risers to aid them in getting on and off seats. Little things really can make a big difference”
Helen, 41

“Never put off what you can do together today”
Christine, 76

“My wife’s illness has shown me the importance of not putting things off until another day, that day may never come. You don’t know what’s around the corner and when I get a chance, and it’s appropriate, I tell people live your life now”
Marcus, 63

“Remember as a carer you need to look after yourself so you can keep caring. Don’t be afraid to ask for help from family and friends. Find out if there is any help out there for you. This will all help you in your role as a carer”
Vee, 56

USEFUL ORGANISATIONS

AccessAble
www.accessable.co.uk

Age UK
www.ageuk.org.uk

Ambulance Wish Foundation UK
www.ambulancewishfoundation.org.uk

Beacon Continuing Healthcare
www.beaconchc.co.uk

British Red Cross
www.redcross.org.uk

Carers UK
www.carersuk.org

Citizens Advice Bureau
www.citizensadvice.org.uk

Compassion in Dying
www.compassionindying.org.uk

Disability Holidays Guide
www.disabilityholidaysguide.com

Farewill
www.farewill.com/pspa-new

Lions Fridge Scheme
www.lionsclubs.co

Motability
www.motability.co.uk

REMAP
www.remap.org.uk

Royal Voluntary Service
www.royalvoluntaryservice.org.uk

SpeakUnique
www.speakunique.co.uk

The Carers Trust
www.carers.org