

Progressive  
Supranuclear Palsy

**PSP**



# **A guide for living with PSP or CBD**

**The PSP Association**

# Life with PSP and CBD: A guide for people who have Progressive Supranuclear Palsy or Cortico Basal Degeneration

Published by The PSP Association © 2008

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# Life with PSP

Having PSP or CBD can be a big change – for you, your family and friends.

However, it is important to remember that

- ❖ Each and every case is different.
- ❖ There is help available so do take advantage of help and support offered.
- ❖ The PSP Association is here to help, through literature, telephone support, clinics, local networks, research and much more.
- ❖ You are not alone and our nurses are at the end of the phone, if you need to talk (see *p40 for contact numbers*).
- ❖ This guide aims to help you cope with PSP/ CBD and make the most of every day.

PSP and CBD are similar conditions and The PSP Association supports both.

In this guide we often use 'PSP' as an abbreviation to cover both PSP and CBD.

## The Early Days – Taking It In

When first diagnosed with PSP there's a lot to take in and you may not have much time to ask the neurologist questions.

There are no easy blood tests or brain scans to diagnose PSP and the range of possible symptoms can make it hard to pin down in the early stages. So it can take time to get an accurate diagnosis and you may even be misdiagnosed at first.

At this time it's understandable that you may feel a range of emotions such as relief, distress, anger, panic, denial or loneliness.

It's important to remember that these feelings are quite normal and usually subside as support becomes available.

Here are a few things to do in the early stages.

Firstly, when you feel ready, **tell** your friends and family about PSP. This will help them to understand and support you. Secondly, make a **list** of questions to ask your GP or neurologist when you see them, to help you plan.



Thirdly, if you haven't already, we recommend that you - or someone close to you – **join** us, so that we can ensure you get the support you need.

Our services include:

- ❖ A 24 hour helpline, linking you to a PSP nurse specialist.
- ❖ Local support groups and networks so you can link up with people who understand your situation.
- ❖ A carers' information pack, full of practical advice for anyone who is supporting you.
- ❖ Our PSP magazine, three times a year, full of the latest news about research and care.
- ❖ Our annual PSP conference.
- ❖ A growing network of PSP / movement disorder clinics around the country.
- ❖ The PSP online forum.

By joining us you will also be part of the world's largest database on PSP, helping us to raise awareness and research for positive change.

# Keeping Positive

Staying positive may be difficult at first, but you should try to live as “normal” a life as possible.

Maintaining independence is crucial to a positive attitude, so below we’ve suggested things to help keep you active and mobile.

Focus on what you *can* do, set yourself short term goals and make the most of each day.

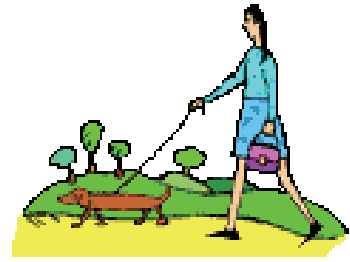
Try to think about your immediate carers, family and friends too. If your symptoms progress, demanding more of their time and energy, what support might they need?



# Keeping Active

Keeping active helps your circulation, muscle tone and sense of wellbeing.

Walking, swimming and stretching are great exercises. If you are a bit unsteady on your feet, why not ask someone to go with you? (It's also more fun that way.)



Exercises such as knee rolling on the bed before going to sleep at night, can help keep the middle of the body more mobile, while balance can be helped with exercises involving moving weight from one leg to the other in standing, stepping and reaching. Breathing exercises are also helpful, and for the neck, looking to the right and left can help prevent stiffness.

Where possible, seek the advice of a physiotherapist, (if you don't have one ask your GP for a referral) to ensure exercises meet your needs and to prevent over-tiring.

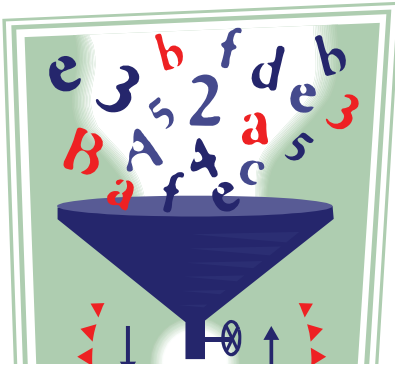


If you feel a bit more tired after exercise, try:

- ❖ Gently massaging your legs and arms. Massage also helps to ease a stiff neck.
- ❖ Stretching exercises, to help your body cool down properly, reducing cramps.
- ❖ Heat pads (available from good pharmacists) or lavender wheat bags that you can heat in the microwave are great for neck and shoulder pain.

Your physiotherapist can advise and you may find regular sessions with a complementary therapist, such as aromatherapy, reflexology or acupuncture, helpful too – nice and relaxing!

## Developing Your Brain Power



In PSP, the build up of ‘tau’ protein in the brain can clog it up. Regular brain work outs can help. Try doing some puzzles, crosswords or *Nintendo* type games every day. Keeping physically active, making time to socialise – the best brain exercise of all – and enjoying a healthy diet, rich with energy-boosting foods such as oily fish, help to keep your brain and body alert.

## Hobbies and Interests

Plan and make time to do the things you enjoy. For example, if you like gardening but feel unsteady on your feet, you can tend your prize displays from your chair (see *the back of this booklet for info about handy suppliers*). Raised beds are ideal for this. Of course, you may prefer to supervise someone else and simply enjoy!



# Home Sweet Home



You may want to think about how adaptable your home is in coping with change. Is there plenty of room to get around? Can it be adapted if needs be?

A bit of planning ahead can make it easier to get the support you need when you need it, as support can take time to arrange.

An occupational therapist can visit you at home and advise you on any adaptations that may be helpful. Don't spend out on expensive items of equipment until you have sought their advice.

## Keeping in Touch

At a time of change we need the support of people who care. Letting people know how they can support you and keeping your social life active helps you to stay positive and reduces the risk of depression or loneliness.



The internet is a great tool for communicating with friends, banking, ordering goods online, finding holidays or renting DVDs. Many supermarket chains have door to door deliveries and some local shops or farmers' markets are doing this too.

Most libraries have computers to use and run low cost or free courses on internet essentials if you're not already online.

Libraries also have details about activities run by your local council or voluntary organisations, who will often organise transport if needed.

Draw up a pen-sheet about yourself with photos: your family, hobbies, career, likes/dislikes. It can help people to be more understanding, break the ice when new people visit you and helps staff get to know you if ever you have a stay in hospital.

## Enjoying a Holiday

With a bit of planning you can enjoy a break with friends and family. Here are a few things to make your time away go smoothly.



- ❖ Go on holiday with others – so there will be plenty of people to support you and to give your immediate carers time off too.
- ❖ Check how accessible the venue is by car, bus or train. What about parking and wheelchair access should you need it?
- ❖ What facilities does the hotel provide?
  - Wheelchair accessible suites?
  - ‘Walk –in’ shower?
  - Wheelchair accessible bathroom?
  - Ramped access to restaurant /bar?
  - Disabled parking?
- ❖ What local amenities are available? Will the hotel arrange day trips or other activities, including indoor or chair based activities if it’s raining or you fancy a rest? (See *p32 for suppliers of activity holidays*)

- ❖ Whether the area is flat or hilly may affect how much you can get around. If you need it, renting an electric wheelchair or scooter could take the strain off you and your companions.
- ❖ Travel insurance – good insurance companies will provide cover for PSP (see p38). Remember to check the small print!
- ❖ Will you need someone to help care for you while away? Some companies will provide carers at your hotel for a reasonable fee, an assessment of risk and a referral from your GP.



# Managing Your Day

## Getting up

Do you sometimes find getting out of bed difficult? Here are some handy ways to help.

Have a loop or hand rail fitted by the bed to help pull you up. If you have CBD, which initially affects one side of the body more, fit the loop on your *best* side and sleep on that side of the bed. (Typical prices: grab rails from £7, over bed pole hoist around £160, rope ladder £10)

Use a pillow elevator – this is a handy headrest that fits under your mattress to raise you at the touch of a button. Available in single or double, the elevator also helps if you want to sleep semi-reclined, for example to help with a troublesome cough. (Typical price: £89, single)



An adjustable bed will also raise you with ease, though a more expensive option. (Typical price £390)

**Again, your OT is the best person to advise you on aids to assist your daily living**

(Note: prices accurate at time of writing)  
See page 36 for a handy list of equipment suppliers

## Getting washed

The sense of smell is not usually affected in PSP, so make the most of the delicious fragrances you enjoy at bath time.



If you find getting in or out of the bath difficult, shower cubicles or wet rooms with side doors for easy access can help, or you could have a hoist fitted to help lift you.

A chiropodist can help if you find looking after your feet or cutting your toenails difficult, while a home hairdressing service can be very convenient.

## Getting dressed

Loose comfortable clothing, Velcro fastenings and elasticated waistbands can help you to get dressed more easily. They're also handy when you need the loo or want to undress to have a wash.

Slip on shoes can save you time too. Make sure they are a comfortable fit so that you don't trip up. If your feet are swollen you may find bootee slippers more helpful. The Soxon stocking aid can help to pull on your socks. (Typical price: £9.37, Betterlife Healthcare).



## Moving about indoors

If you are unsteady on your feet around the home here are a few tips to keep you safe:

- ❖ Use padding on furniture (or your hips! Hip shields £61.00) to protect yourself against sharp corners.



- ❖ Use a walker for extra support. Heavy duty walkers distribute your weight more evenly than lightweight ones; consult your Occupational Therapist for information. (If you are not registered with an OT ask your GP to refer you.)

- ❖ Built up shoes or inserts can help keep you leaning forwards if you feel at risk of falling backwards.

- ❖ A fall detector is a handy device that fits to your clothing to alert you or others if you are likely to fall.



- ❖ Wearing a personal pendant alarm or a lifeline home unit can give you, and your loved ones, peace of mind, putting you in touch with a trained operator in seconds if ever you need to alert someone.

- ❖ Have an emergency lifting cushion nearby – it can be put under you to inflate and lift if ever you need it.

## Getting out of a chair

If you struggle to get out of a chair:

- ❖ Use a raised cushion so that you sit higher up
- ❖ 'Rising recliner' chairs cost more but can raise you easily at the touch of a button
- ❖ High backed chairs with a neck support are also handy if you have a stiff or weak neck.



If you are a bit unsteady on your feet, try to have someone with you when walking on uneven pavements or crossing the road.

Avoid using the stairs if you have a tendency to fall. Talk to your OT about using a ground floor room as a bedroom.

If you don't have a main carer, find someone who will keep in touch and check up on you from time to time.

Panic alarms are also handy to let someone know if you need help.

## Vision on

PSP can affect eyesight in several ways, though not usually all at once. You may find it hard to look up or down or to focus, which can make it harder to read, watch television or tie up shoelaces. Here are some ways to help:

- ❖ Remove potential trip hazards, keep things you need such as call buzzers or remote controls within your field of vision, and have your TV fitted at eye level.
- ❖ Prism glasses can sometimes help. Contact your *Orthoptist*, for advice.
- ❖ If you are sensitive to bright light, wrap around sunglasses or solar shields (which can go over your glasses) help to reduce the glare.
- ❖ If you have dry eyes you will need to use artificial tears regularly to keep them moist (from your GP).
- ❖ If you find it difficult to maintain eye contact or conversely, tend to stare, explain to family and friends that you are not being rude, this is just a phase of PSP that some people experience.
- ❖ Wearing a patch over one eye or lens can help tackle double vision.
- ❖ If your eyes tend to close or screw up a lot, a dose of Botox may be helpful; discuss this with your neurologist.



## Speaking up

Sometimes PSP can affect the way we think and our ability to talk. Speech & Language Therapists are trained to help tackle this in the best way for you, so we would always recommend that you consult one if you are experiencing any kind of problem. Some of the tactics which can help include:

- ❖ Thinking 'LOUD' will increase your volume if you tend to talk in a whisper. Voice amplifiers and telephones to amplify speech are also available.
- ❖ Using pacing boards and pausing can help tackle problems with rhythm, stammering or repetition.
- ❖ If you find it hard to do several things at once or it takes you time to gather your thoughts, try doing things one at a time to allow you to focus. Ask friends to give you more time to respond in a conversation.



If talking is really troublesome there are other devices too such as light readers or communication aids which can help – consult your Speech and Language Therapist (SLT) for advice.

## Enjoying your food

A healthy diet is good for you so enjoy plenty of fruit, vegetables, the foods you like and plenty to drink throughout the day. Here are some tips to make the most of your meals:



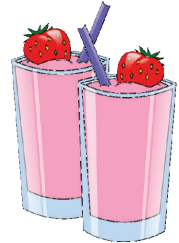
If you are forgetful or unsteady on your feet, arrange for someone to cook for you. There are many good meal delivery services now (see page 38).

If food keeps going down the wrong way:

- ❖ Take smaller mouthfuls.
- ❖ Cut food into bite size, even pieces.
- ❖ Avoid dry, crumbly or chewy food such as toast or biscuits which could make you cough.
- ❖ Use thickeners to make liquid or soups a bit thicker so they go down evenly. These are available from any good pharmacy.
- ❖ Cranberry juice works well with thickeners and has a good sharp taste – it's great for the bladder too.

❖ Liquidise really chunky soups or troublesome food. (If you liquidise food, do each food separately so that you can enjoy a proper, colourful meal.)

❖ Make a fruit smoothie so that you can enjoy your favourite fruit or vegetables.



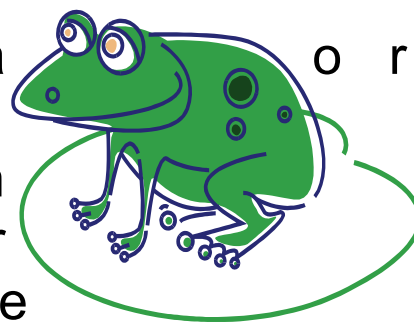
❖ The trick is to make the food as even as possible so that it goes down easily without making you cough.

If you find it hard to look up or down through PSP, you may miss the enticing food nearest you on your plate.

A plate surround, that clips on to any dinner plate and costs around £3.00, can be very helpful if you find it hard to look down. Using an over-the-bed table, raised up so you can see your plate, is another tip. You could also ask a friend to rotate your plate just in case.

## Pesky frog?

If you are having trouble with saliva clearing your throat, try cutting down on dairy products (which can thicken secretions), sip hot water with slices of lemon or orange juice (which can thin them) or try inhaling steam.



We also have an information sheet on dealing with saliva that we can send you.

Your speech and language therapist can also advise on helpful ways to manage mealtimes.

*Our 'Under the Magnolia Tree' Cookbook is bursting with tasty, easy-to-eat recipes for the whole family, particularly for anyone with swallowing difficulties. Phone 01327 322419 to order your copy.*

## Getting a good night's sleep

If you are unsettled at night or struggling with broken sleep, consult your GP as a sedative at night may be helpful in the short term.

Try to establish a routine of going to bed/waking at the same time each night/day.

A warm (not hot) bath may relax you before sleep.

Try to avoid caffeine late in the day as this can prevent sleep.

A drop of lavender or chamomile oil on your pillow may relax you, or you could try drinking chamomile tea.



If you are getting out of bed unawares a pressure mattress or handy movement detector under your pillow or mattress will let others know so they can keep an eye on you.

Protective side bars will also stop you falling out of bed if you are taking sleepwalking too far!



If you cough a lot at night, using an extra pillow to raise you up can help ease this.

## Spending a penny?

You may find your sleep is disturbed by the need to go to the loo frequently. You could have a commode nearby or gents can use a urinal to save the trip to the bathroom each time.

If problems persist, it's worth checking with your district nurse, to rule out other causes such as an infection or enlarged prostate. She/he can then refer you on to a continence nurse advisor if necessary. Often there are medications which can help.

Constipation can be a problem with PSP. Ensure you are drinking plenty of fluids throughout the day.



Even with a well balanced diet with fresh fruit and vegetables, you may find you need to take regular laxatives. You can discuss this with your GP or nurse specialist.

Your occupational therapist can also advise if you need equipment such as grab rails or a raised toilet seat if you are less mobile.

# Getting About

## Driving

PSP can affect eyesight and weaken ability to judge distance. Passengers may find your swerving unnerving, so it is wise to let others drive you where you can. You must, in any event, notify the DVLA if you have PSP.



## Shopping



Check with your local Council about their mobility scheme, to help you get to and from your local shops. This includes buses or drivers to take you door to door. Some charities also run free or low cost schemes using volunteer drivers.

If you are unsteady on your feet, ask someone to go with you when using stairs or crossing the road, or why not hire a wheelchair for the day to take the strain?

## Changes In How You Feel

Sometimes PSP can affect the way we think and feel, causing us to cry or laugh when we don't really want to, or to feel irritable, muddled or unenthusiastic at times.

It can also cause loss of concentration, lack of judgement or 'reckless' behaviour, such as getting out of a chair or walking too quickly, which can lead to falls and injury.



If you are experiencing any of these things, relax, it's not *you*, it's the condition you happen to have. Telling your friends and family how you feel can help them to understand and support you - and keep an eye out for changes.

There are also practical things to help, such as movement detectors to let others know if you are going somewhere, or a reminder gadget to prompt you if a meal, drink or tablet needs to be taken at a certain time of the day (*see p37 for suppliers*).

Feeling a bit low in the early days is understandable, but if it continues it's worth getting checked out as there are effective treatments and therapies that can help. Consult your GP for more information.

## Getting The Help You Need

Finding a carer, financial support and equipment can take time to arrange, so start thinking now about any help you may need.

Getting the right support you need doesn't always happen first time around, so do persevere. Once you are in the system things become easier.

Local authorities have a duty to ensure you get the support you need and should carry out a needs assessment. You are entitled to your own assessment, as is your main carer if they care for you more than 35 hours a week.

Some areas will allocate a case manager from the NHS or Social Services to support you.

Help that is identified as health care is provided by the NHS free of charge, while social care is provided by the Local Authority and is often means tested. Your health care needs will probably increase as PSP progresses. When the primary need is health care, responsibility transfers to the NHS – this becomes 'continuing care' and is usually free of charge.

Prepare for any meetings by listing the questions you want to ask. What do you want to get from the meeting? What will the health/welfare professional need to know in order to give you the best support?

This could include information about PSP, your needs, and PSP Association contact numbers. Think about tomorrow's needs as well as today's – PSP is progressive and assistance can take time to organise.

Be open about your needs and press your case politely, clearly and firmly.

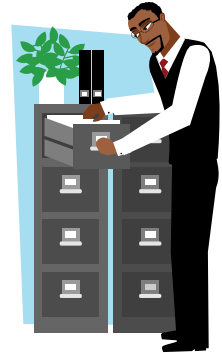
If you – or professionals supporting you - need further advice, our specialist team are here to help. Contact the PSP number(s) at the end of this booklet.

Keeping a diary can help back up any claim. Keep a one day diary to track more detailed needs or if the help you need changes each day/night, keep a record over a week or longer. What help do you need and why? What time do you need it and for how long? Give a copy to your GP or other professional supporting you and keep a copy for yourself.

Remember - when filling in forms, think about how PSP affects you or your family on your *most difficult day*, in order to plan the level of support you need when you most need it.

# Staying In Work

An early diagnosis of PSP or CBD does not mean you will have to stop working immediately, though it is important to be realistic about what you will be able to continue to do.

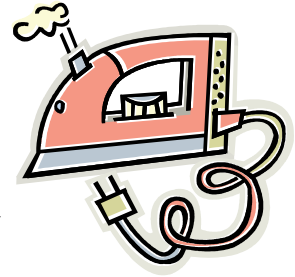


The Disability Employment Adviser at your local Job Centre Plus can advise you on benefits and support at work through the 'Access to Work' scheme, such as help with travel to and from work, aids or a support worker to help in the workplace.



## Financial Support and Care

You may find that you need a bit more help with household tasks, such as washing and ironing, cleaning and gardening, or with managing your personal hygiene.



There are various benefits which may help and you may need an OT's assessment first. The main ones relevant to PSP or CBD are:

- ❖ Incapacity Benefit – if you can't work and have not reached State Retirement Age (depending on your level of national insurance contributions)
- ❖ Carers Allowance – if you care for someone more than 35 hours a week
- ❖ Disability Living Allowance – if you are disabled and apply before you reach 65
- ❖ Attendance Allowance – if you are disabled and are over 65
- ❖ Income support – to raise your total income to a certain level if you are under 60 (this is means tested)
- ❖ Pension Credit – to increase your income to a certain level if you are over 60 (this is means tested)

You may be entitled to other support:

- Council tax reductions
- Council tax benefit
- Housing benefit
- Housing adaptations and equipment
- Blue badge for your car
- Exemption from road tax
- Disabled person's railcard
- Bus discounts
- Free prescriptions
- Free eye tests and subsidised glasses
- Free talking books and newspapers
- Refunded costs for travel to hospital



See our leaflet '*Work, Benefits and Finance*' for more information.

Some charities also offer support and many professions or trades have their own charities that may be able to help. For a helpful list of organisations, please visit [www.aco.uk.net/allmembers.asp](http://www.aco.uk.net/allmembers.asp)



# Handy Contacts

## **Active holidays for people with a disability**

Jubilee Sailing Trust- Tall Ship sailing breaks

Tel: 02380 449180 [www.jst.org.uk](http://www.jst.org.uk)

Calvert Trust (Exmoor) - Accessible outdoor activity breaks. Tel: 01598 763221

Disabled Holiday Information

[www.disabledholidayinfo.org.uk](http://www.disabledholidayinfo.org.uk)

## **Age UK (Formerly Age Concern & Help the Aged)**

Contact 0800 00 99 66 to find your local branch

## **Aromatherapy**

Find a qualified therapist near you at:

[www.ifaroma.org](http://www.ifaroma.org) Tel: 0208 8409288

## **Audio equipment / books**

Local Library

Access to a range of spoken word cassettes and CDs through its interlibrary loans scheme.

Calibre

Audio books loan service - Audio books, CD, Cassette, MP3 format or digital. Over 8000 to choose from. [www.calibre.org.uk](http://www.calibre.org.uk) Tel: 01296 432 339

## Listening Books:

Tel: 020 7407 9417 or [www.listening-books.org.uk](http://www.listening-books.org.uk)

## RNIB Talking Book Service

Unabridged books in a special CD format with the capacity to hold a whole novel. Tel: 0845 762 6843 or [www.rnib.org.uk/talkingbooks](http://www.rnib.org.uk/talkingbooks)

## Talking Newspaper Association:

National newspapers and magazines on cassette tape and in electronic format. Tel: 01435 866 102 or [www.tnauk.org.uk](http://www.tnauk.org.uk) [www.revealweb.org.uk](http://www.revealweb.org.uk) is the national database of accessible audio resources.

## **Benefits advice / Finance**

- Incapacity Benefit ( 0800 055 6688)
- Carers Allowance (01253 856 123)
- Disability Living Allowance ( 0800 88 22 00, benefits enquiry line)
- Attendance Allowance (0800 882200)
- Income support (0800 055 6688)
- Pension Credit (0800 99 1234)
- Council Tax Reductions (contact your local council)
- Council Tax Benefit (contact your local council)
- Housing Benefit (contact your local council)
- Housing Adaptations and Equipment (Contact Adult Services at local council)
- Blue Badge for your car (contact your local council)

- Exemption from Vehicle Excise Duty (0845 712 3456)
- Disabled Person's Railcard (08457 484950)
- Bus discounts (contact your local council)
- Free prescriptions (GP)
- Free eye tests and subsidised glasses/contact lenses (optician)
- Free talking books and newspapers
- Refunded costs for travel to hospital (PALS in your hospital)

### **Carers** - finding a carer

In the first instance, approach the social services department of your local council to arrange a health and social care assessment. Usually an OT will assess what sort of care you will need. The direct.gov website has a wealth of information, see the link below.

[www.direct.gov.uk/en/DisabledPeople/HealthAndSupport/ArrangingHealthAndSocialCare](http://www.direct.gov.uk/en/DisabledPeople/HealthAndSupport/ArrangingHealthAndSocialCare)

### Helping hands and Homecare agency

[www.helpinghandshomecare.co.uk](http://www.helpinghandshomecare.co.uk)

Tel: 0808 180 9488

### Carers UK

To find your local branch contact 0207 490 8818 or [www.carersuk.org](http://www.carersuk.org) (click on information then finding help)

### Carers when on holiday

Strand Nurses: provide nurses/ carers to accompany you on holiday. Tel. 0207 8366396

[www.strandnursesbureau.co.uk](http://www.strandnursesbureau.co.uk)

### Vitalise

Specially adapted holiday centres for all the family, can provide 24/7 nursing care. 0845 345 1972

[www.vitalise.org.uk](http://www.vitalise.org.uk)

### Citizen's Advice Bureau

[www.citizensadvice.org.uk/](http://www.citizensadvice.org.uk/)

Crossroads - support for you when your carer goes out. Tel: 0845 450 0350

### **Communication Aid Centres**

NHS Communication Aid Centre. Phone 0117 975 3946 or [www.cacfrenchay.nhs.uk](http://www.cacfrenchay.nhs.uk) (click on 'other services', other communication aid centres')

### **Disability Rights Handbook**

Published by the Disability Alliance.

Tel: 020 7247 8776 or [www.disabilityalliance.org](http://www.disabilityalliance.org)

### **The Disabled Living Foundation**

Provide free, impartial advice about all types of disability equipment and mobility products. Contact: 0845 130 9177 (charged at local rate) or [www.dlf.org.uk](http://www.dlf.org.uk)

## **Equipment:**

- Pillow elevator
- Protective padding for you / your home
- Riser cushion
- Solar shields – to protect from bright light
- Wheelchairs – hiring and buying
- Weighted walkers
- Sock grip / puller-upper
- Voice amplifiers
- BT amplifier telephones
- Adjustable Bed
- Fall detectors
- Over bed pole hoist
- Meal time aids
- Over chair/bed table

## **Equipment Suppliers**

Age UK (Help the Aged)

Tel: 0800 169 1609. They also have an online shop  
[www.helptheagedshop.co.uk](http://www.helptheagedshop.co.uk)

Assist

[www.assist-uk.org](http://www.assist-uk.org) Tel: 0870 770 2866

Better life healthcare

[www.betterlifehealthcare.com](http://www.betterlifehealthcare.com) Tel: 0800 328 9338

BT Shop

[www.shop.bt.com](http://www.shop.bt.com) Tel: 0800 800 150

## Great British Mobility

Suppliers of chairs, beds, baths and scooters.

Tel: 0800 980 0978

[www.greatbritishmobility.com](http://www.greatbritishmobility.com)

## Handy healthcare

[www.handyhealthcare.co.uk](http://www.handyhealthcare.co.uk) Tel: 0844 3570382

## RNIB

Equipment and support for sight problems.

Tel: 0303 123 9999 or visit [www.rnib.org.uk](http://www.rnib.org.uk) for advice.

## Toby Churchill

Lightwriters, voice amplifiers, digital speech recording aids, and other communication aids.

Tel: 01954 281210 [www.toby-churchill.com](http://www.toby-churchill.com)

## Tunstall Telecare Equipment

Tel: 01634 846 209 or [www.telecare.org.uk](http://www.telecare.org.uk)

Supply fall detectors, personal pendant alarms, PIR Movement detectors, and reminder gadgets. A guide is available from [www.tunstall.co.uk/guides](http://www.tunstall.co.uk/guides) or call 01977 660206. A guide to **telecare** booklet UK9015 is available from [www.carersuk.org/information/orderpublications](http://www.carersuk.org/information/orderpublications) or call 0808 808 7777 / 0207 7378 4999

## **Gardening aids**

### Able Gardener

Tel: 01738 639222 [www.ablegardener.co.uk](http://www.ablegardener.co.uk)

## Garden Tools for All Seasons

[www.gardentoolsforallseasons.com/](http://www.gardentoolsforallseasons.com/)

## **Government helplines**

(For example, advice on money, tax and benefits)

[www.direct.gov.uk](http://www.direct.gov.uk)

## **Insurance**

### Saga

Tel: 0800 373 034

[www.saga.co.uk/finance/travelinsurance](http://www.saga.co.uk/finance/travelinsurance)

### Age Concern – England

Tel: 0845 601 3333 [www.ageconcern.org.uk](http://www.ageconcern.org.uk)

### Chartwell Insurance

Tel: 0845 260 7051/2 [www.chartwellinsurance.co.uk](http://www.chartwellinsurance.co.uk)

## **Meal Delivery Services**

### Wiltshire Farm Foods

Delivering freshly cooked, frozen meals to your do.

Call for a brochure: 0800 773773

### Oakhouse foods

Delivering freshly cooked frozen meals to your door.

Call for a brochure: 0845 6432009

### Meals on Wheels

Contact your local Social Services to see if you are eligible.

## **Medic Alert**

Medical alert jewellery, which helps medical personnel know important information about you/your condition, should an emergency arise.

Tel: 020 7833 3034 [www.medicalert.org.uk](http://www.medicalert.org.uk)

## **Mobility Schemes**

Motability Scheme enables disabled people to use their government-funded mobility allowances to obtain a new car, powered wheelchair or scooter.

[www.motability.co.uk](http://www.motability.co.uk) Tel: 0845 456 4566

## Shopmobility

Tel: 0845 644 2446 [www.shopmobilityuk.org](http://www.shopmobilityuk.org)

Email: [info@shopmobilityuk.org](mailto:info@shopmobilityuk.org)

## **Physiotherapy**

The Chartered Society of Physiotherapists

Tel: 020 7306 6666 [www.csp.org.uk](http://www.csp.org.uk).

*We hope you find this booklet a helpful resource. Whilst every effort has been made to ensure the accuracy of content, the information contained does not necessarily reflect the views or policies of The PSP Association and the Association can take no responsibility for any error or omission. Likewise, any suppliers mentioned are given as examples and not endorsed by The PSP Association itself. We would always recommend that you consult your GP or relevant specialist before embarking on any course of action in connection with PSP or CBD.*

Support and information from The PSP Association:

**PSP Head Office:** 01327 322410

**PSP Support Information Line:**

Tel: 01327 322415

(9am-3pm; or leave a message on the answerphone).

Give us a call if we can be of service. We have a range of information, including the:

- ❖ Carers Information Pack (CIP)
- ❖ Care and Support leaflet (general)
- ❖ Clinic posters
- ❖ Guide to PSP and CBD (a copy is included in the CIP)
- ❖ Information pack for professionals (PIP)
- ❖ Magnolia Cook book – bursting with tasty recipes for anyone with swallowing difficulties

See our website for helpful information:

[www.pspeur.org](http://www.pspeur.org)

**PSP Nurse Specialists:**

Kat Haines - Tel: 01995 601533

Jill Lyons - Tel: 01934 842366

Samantha Pavey - Tel: 01747 841461

Katie Rigg - Tel: 01434 382564

**Working for a world free of PSP**

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