

# Dementia: the Carer's Experience

*Better Enabled, Better Equipped*

## A Dementia Checklist

**A Resource by Carers for Carers**

May 2018, East Lothian



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## **Dementia Checklist**

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## Foreword

Following the successful conference for carers of people with dementia in Glasgow in 2017, a group of us in East Lothian have had the opportunity to organise a second conference from an East Lothian perspective. I am a member of this group and we have compiled a similar resource to that produced for the Glasgow event – **A Dementia Checklist: A Resource by Carers for Carers.**

Although this list is not exhaustive, we have aimed to offer as up-to-date and as accurate information as possible. We hope this will help you navigate your way through the many challenges which a diagnosis of dementia brings and find your own way of getting some control back into your life whilst living with often very difficult experiences and feelings.

We are all carers and share similar yet also very different experiences, from living with the impact of diagnosis (and pre-diagnosis) to travelling the unknown and hugely challenging and varied journey ahead. Each family and story is different and individual. Yet there is something comforting to find that we are not alone and that there are many resources of help and support in our communities. Information and education are power in what can often feel like a chaotic situation.

Therefore we offer and share our East Lothian version of a **Dementia Checklist**, which builds on the version produced for the Glasgow event. We hope it will provide a place from which to make your own choices about where to find help and advice and be able to pass on information to others if required. Talking and sharing really does help and often we can be pointed in a direction which we hadn't previously considered. There are a lot of practical and financial suggestions which could be helpful. None of us needs to travel this journey on our own. We all care and are carers.

I would also like to make a special mention of Katharyn Barnett, who was a member of the steering group for the Glasgow event, and who had the original idea for the checklist, which she compiled whilst caring for her mother so thank you, Katharyn, for sharing your knowledge with us.

We have included Katharyn's foreword to the Glasgow checklist by way of thanks and introduction.

Keep talking, seeking and sharing....

Thank you

**Moyra Birnie**  
**East Lothian Carers Event Steering Group**

## Foreword to the Glasgow Dementia Checklist, by Katharyn Barnett

My Mum was diagnosed with dementia in 1995. It took me ten years to build a team around Mum to enable her to live a happy, connected and fulfilled life right to the end. I learned to identify the right support so that we could access it as and when we needed.

Good care management is a bit like conducting an orchestra. You might not want all the musicians playing all the time, but you need to know where they are! Everyone's experience of dementia is different; every family faces different challenges and has their own way of meeting them.

This list is not exhaustive but it's a checklist that I put together in the hope that it would provide a starting point. Because once you have the essentials in place, once you know where to go to get help if and when you need it, you can begin to do dementia your way, rather than let an illness dictate your life.

I think of this as 'Laura's List' because Mum was passionate about education – and education is all about sharing what we know so we can all learn to do things better. Others have contributed to it, and shared some great ideas.

So I hope that you can take it, improve it and make 'Laura's List' your own working directory of care.

Then, just pass those good ideas on...

**Katharyn Barnett**  
**Glasgow Carers Conference Steering Group**

## Acknowledgements

Contributors to this updated **Dementia Checklist**, produced for the East Lothian Carers Event, are:

- Moyra Birnie
- Anne Bisset
- Alison Reynolds
- Mike Turnbull

Alison, Anne, Mike and Moyra have long experience of caring for someone with dementia, unpaid. This **Dementia Checklist** is their work.

The **Dementia Checklist** and also a **Local Directory** of services, groups and activities were first produced by the Glasgow Carers Conference Steering Group for carers attending their conference, **Dementia: the Carer's Experience**, held on 30 September 2017 in Glasgow. The first **Local Directory** covered the areas of East Dunbartonshire, East Renfrewshire, Glasgow, North Lanarkshire, South Lanarkshire, Renfrewshire and West Dunbartonshire. An East Lothian version of Dementia – A Carers Local Directory was also produced by the East Lothian Carers Event Steering Group. This was for carers attending their event, Dementia: the Carer's Experience, on 22 May 2018 in North Berwick.

The **Dementia Checklist** and the **Local Directory** for East Lothian are complementary, peer to peer resources. They both provide practical information which the Steering Group, from lived experience, recognise as relevant and useful for others in the same caring situation.

The **Dementia Checklist** and both of the regional **Local Directories** can be downloaded from the Life Changes Trust website – <https://www.lifechangestrust.org.uk/projects/conferences-and-carers>

Along with Katharyn Barnett, as the initiator, other contributors to the first **Dementia Checklist** and **Local Directory** for Glasgow were:

- Myra Lamont
- Maureen McKillop
- Bernard O'Hagan
- Anne Rankin
- Annette Tait

Katharyn, Myra, Maureen, Bernard, Anne and Annette too had long term experience of caring for someone with dementia, unpaid.

## Introduction

The Life Changes Trust believes that carers in Scotland have an enormous amount of knowledge and helpful information to share with each other.

In the spirit of empowerment, the Trust is funding and supporting carers of people living with dementia to run their own local events in communities around Scotland. These events have carers at their heart, leading the way – events designed for carers, by carers.

The first conference of this type was held in Glasgow in September 2017, planned and organised by a steering group of people with long experience of caring for someone living with dementia, unpaid.

The Trust similarly invited carers in East Lothian to form a steering group, again supported and funded by the Trust, to come together to plan and organise as they saw fit an event for carers in East Lothian. The group first met in January 2018. **By carers for carers** has been the enduring theme of their hard work over the past few months.

The **Dementia Checklist** has been updated by the East Lothian Carers Event Steering Group to give to carers attending the group's conference, **Dementia: the Carer's Experience**, on 22 May 2018.

### East Lothian Carers Event Steering Group

- Moyra Birnie
- Anne Bisset
- Alison Reynolds

With acknowledgement also to the contribution of: Mike Turnbull.

With support from: Elizabeth Morrison, Funding and Carers Programme Manager, Life Changes Trust

Amanda McCarren, National Carer Engagement Lead, and Beau Nieuwenhuijs and Lorraine Bairstow, Regional Carer Engagement Leads, tide (together in dementia everyday).

# 1. Impact of Carers (Scotland) Act 2016

The introduction of the Carers (Scotland) Act 2016 will have a significant impact on unpaid carers and be a key part of changes to how benefits are given (see Money Matters section below for more information), as well as how each local authority and health and social care partnership implement the Act in their area. Below is a summary of the key points of the Act and some useful links to additional information.

## Summary

The Carers (Scotland) Act 2016 takes effect from April 1, 2018 to ensure better and more consistent support for carers so that they can continue to care, if they so wish, in better health and to have a life alongside caring.

From 1 April 2018 there is:

- A new right for carers to be offered, or request, an Adult Carer Support Plan (ACSP) or Young Carer Statement (YCS), setting out their personal outcomes and identified needs.
- A duty for local authorities to provide support to carers, based on the carer's needs which meet the local eligibility criteria. They also have a power to provide support to meet carers' needs which don't meet these criteria.
- A requirement for local authorities to establish and maintain an information and advice service for carers.
- A duty on local authorities to publish and review a short breaks services statement.
- A duty for local authorities and health boards to 'take such steps as they consider appropriate' to involve carers and carer representatives in the planning and evaluation of services that support carers, including the preparation of the local carer strategy.
- A requirement for the responsible local authority to consider support in the form of a break from caring, and the desirability of breaks from caring provided on a planned basis.
- A duty on health boards to inform the carer and to invite their views before a cared-for person is discharged from hospital. Their views must be taken into account before the discharge of the cared-for person.
- The publication of a carers' charter to accompany the Act, which sets out the rights of carers in or under the Act.

## Useful Links

Use these links to help you find more information:

**Scottish Government Carers Policy** – information on the various components of the Act, along with the currently active programmes and initiatives undertaken by the Scottish Government and external stakeholders – <http://www.gov.scot/Topics/Health/Support-Social-Care/Unpaid-Carers>

The finalised **statutory guidance** – <http://www.gov.scot/Publications/2018/03/5082>

The **Carer's charter** – <http://www.gov.scot/Publications/2018/03/4874>

**Carers (Scotland) Act 2016** – the full legislation for the Carers (Scotland) Act 2016 can be found here – <http://www.legislation.gov.uk/asp/2016/9/contents/enacted>

**Young Carer infographic** – this is an excellent infographic created by Young Scot, which explains how the Act might affect young carers: <https://www.youngscot.org/information/rights/carers-act/>

**Misc. Resources** – a variety of reports commissioned by Scottish Government to assist with implementing the Act. They include a report on Personal Outcomes by Emma Miller, an Evidence Review by Ailsa Cook and Scotland's Carers, a report bringing together statistical analysis and research on caring – <http://www.gov.scot/Topics/Health/Support-Social-Care/Unpaid-Carers/Implementation/UsefulResources>

Coalition of Carers in Scotland – Carers Act Resources – a series of leaflets for carers can be found on the Coalition's website: <http://www.carersnet.org/carers-act-resources/>

To access unbranded versions of the leaflets, for adapting for local use, contact the Coalition directly – please email: [coalition@carersnet.org](mailto:coalition@carersnet.org)

## 2. Money matters

### Social Security Changes (section updated post-event – Feb 2019)

The Scotland Act (2016) transferred new social security powers to the Scottish Parliament, allowing Scottish Ministers to develop new policies on benefits that will help tackle inequality and poverty in Scotland.

This led to the creation of The Social Security (Scotland) Bill which was published on 21 June 2017. The Social Security (Scotland) Bill established a framework for delivering benefits devolved by The Scotland Act 2016 and introducing new forms of assistance. These included:

- Attendance Allowance
- Carer's Allowance
- Carer's Allowance Supplement (new)
- Young Carer Grant (new)
- Disability Living Allowance
- Personal Independence Payments
- Industrial Injuries Disablement Benefit
- Severe Disablement Allowance
- Cold Weather Payments
- Winter Fuel Payments
- Funeral Expenses Assistance
- Best Start Grant.

**The Social Security (Scotland) Act 2018** received Royal Assent in June 2018. In general terms, when a new Act actually comes into effect may vary and different provisions may come into force at different times. In this case, different rules about each type of assistance will be contained in regulations.

The Scottish Government has created a new Social Security Agency in Scotland which will be responsible for administering the devolved benefits and new forms of assistance: **Social Security Scotland**.

Its headquarters are in Dundee, with a second base in Glasgow. Once fully operational, it will provide a local presence in communities across Scotland, providing face-to-face support and advice, supported by centralised administrative functions.

### Useful Links

Use these links to help you find more information:

**Scottish Government Social Security Policy** – information on various aspects of policy and action being taken – <https://www.gov.scot/policies/social-security/>

**Support for Carers** – this Scottish Government policy position paper sets out the next steps for carer benefits in Scotland – <https://www.gov.scot/publications/support-carers-policy-position-paper/>

**Social Security Scotland** – the website of the new Agency includes latest updates – <https://www.socialsecurity.gov.scot/>

**Carers Allowance Supplement** - <https://www.mygov.scot/carers-allowance-supplement/>

### Attendance Allowance

Attendance Allowance is a non-means tested benefit paid to people aged 65 or over, based on their needs. Having a diagnosis of dementia does not automatically qualify someone for Attendance Allowance. Attendance Allowance is paid at two rates: £57.30 per week lower rate 2018/19 and £85.60 per week higher rate for those whose needs are more severe (2018/19).

Age Scotland has an excellent booklet that explains eligibility criteria. For more information, call the Age Scotland helpline on 0800 12 44 222.

- **To claim:** you can download Attendance Allowance forms and complete them yourself or you might prefer to contact your local Citizen's Advice Bureau or your local Carers Centre for assistance.
- Please remember that Attendance Allowance is paid per person, not per household. If you are caring for someone with dementia, but you also have health problems for which you need support and you are aged 65 or older, you might be entitled to claim Attendance Allowance in your own right.

## Carer's Allowance

Carer's Allowance is paid at a rate of £64.60 per week (2018/19) to carers of people who already receive Personal Independence Payment, Disability Living Allowance or Attendance Allowance. If the person for whom you care does not receive any benefits, you cannot claim Carer's Allowance. Carers who earn over £120 a week (after deductions) or who receive a state pension are not awarded Carer's Allowance.

## New Carer's Allowance Supplement

From April 2018 in Scotland, a Carer's Allowance Supplement payment will be paid in addition to Carer's Allowance – see <https://www.mygov.scot/carers-allowance-supplement/>

This is an extra payment for carers in Scotland who already get Carer's Allowance on a particular date.

Carer's Allowance Supplement is paid twice a year. The next two rounds of payments are:

- £226.20 in June 2019 – you will get this payment if you're getting Carer's Allowance on 15 April 2019
- £226.20 in December 2019 – you will get this payment if you're getting Carer's Allowance on 14 October 2019.

If you're due to get a payment, you will get a letter from Social Security Scotland before the payment is made. You can contact a helpline advisor at Social Security Scotland for more information on 0800 182 2222.

## New Young Carer Grant

Young carers in Scotland may be eligible for a new annual payment of £300 to help them access life opportunities that are the norm for other young people.

Alongside wider Scottish Government support for young carers, it is intended that the grant will help young carers to:

- look after their own health and well-being, improve their quality of life and reduce any negative impact of caring
- participate fully in society and, if they choose, engage in training, education and employment opportunities, as well as social and leisure, and
- have an increased sense of control and empowerment over their lives.

The Young Carer Grant will be paid to young carers with significant caring responsibilities – to 16 and 17 year olds, and 18 year olds if at school, who are:

- caring for someone in receipt of the middle or higher rates of Disability Living Allowance, Attendance Allowance or Armed Forces Independence Payment
- caring on average for 16 hours per week, over a three month period, and
- not in receipt of Carer's Allowance.

The Young Carer Grant will be paid from autumn 2019 and will be paid on an entitlement, rather than discretionary, basis. Like all parts of Carer's Assistance, it will be up-rated annually.

Recipients of the Young Carer Grant will also be eligible for **free concessionary bus travel** in Scotland from 2020/2021, subject to successful piloting.

For more information, visit Young Scot – <https://young.scot/information/rights/young-carer-grant/>

### Disability Living Allowance (DLA)/Personal Independence Payment (PIP)

DLA and PIP are benefits that are paid to people with dementia who are under the age of 65 years. PIP took over from DLA but, like DLA, the award is based on an assessment of need rather than a diagnosis. If you are caring for someone with early onset dementia, you need to consider claiming PIP. Citizens Advice Bureaux, Carers Centres and Dementia Resource Centres can advise.

### Council Tax Rebates

Most local authorities offer Council Tax Rebates for anyone living with 'severe mental impairment'.

- Depending on the local authority, the rebate might be 100% for sole occupancy or 25% to 50% rebate for two people in the same household where one has a severe mental impairment. If there are more than two people living in the household, it is likely that there will be no reduction in Council Tax.
- If you have had to make substantial alterations to your house because you are caring for someone who is also physically disabled, you might also be entitled to a reduction in Council Tax.

Age UK provide clear guidelines on benefits for unpaid carers and for people living with dementia – <http://www.ageuk.org.uk/home-and-care/caring-for-someone-with-dementia/getting-support/>

## TV Licence Concession

If you're 75 or older, you may be entitled to a free over 75 TV Licence. It covers you as well as anyone you live with.

If a person is blind (severely sight impaired) and you can provide evidence, you are eligible to apply for a 50% concession on your TV licence. If you are partially sighted (sight impaired) you are not eligible. If you already have a TV licence but it isn't in the name of the person who is blind, you will need to transfer it. For more information, see – <https://www.tvlicensing.co.uk/check-if-you-need-one/for-your-home>

## Home Energy

Consider checking your **tariff** to ensure that you have the best rate. If you are spending more time indoors and at home, or you are doing more laundry, it is surprising how costs can increase.

Home Energy Scotland is a Scottish Government programme managed by Energy Saving Trust. A network of local advice centres, covering all of Scotland, offer free, impartial advice on energy saving, renewable energy, sustainable transport and waste prevention. They advise on how to make your home warmer, and save energy and money. The helpline number is 0808 808 2282 and all calls are free. See – <https://www.energysavingtrust.org.uk/scotland/home-energy-scotland>

# 3. Working and caring

## Flexible Working

As a carer, you have the right to ask your employer for unpaid leave to accompany a dependent to medical appointments and to request flexible working hours. The employer can refuse, but many would prefer to try to accommodate a long-standing and experienced employee rather than recruit a replacement. Ask your employer if the organisation has a carers employment policy (also called a carers leave policy or a dependents policy).

## 4. Legal matters

### Power of Attorney (Enduring and Welfare)

A Power of Attorney is a written document giving someone else authority to take actions or make decisions on your behalf.

This could be to deal with financial affairs and/or welfare matters. It is a powerful document that helps to safeguard the interests of people with dementia by enabling those who know them best to articulate their stated wishes, if and when they are unable to do so.

The Power of Attorney names the Attorney/s and lists the powers that they have (i.e. the areas in which they can take decisions). The Power of Attorney will also state when Attorneys can begin acting.

Go to the **Office of the Public Guardian** to understand what Power of Attorney involves – <http://www.publicguardian-scotland.gov.uk/>

The Office of the Public Guardian will also direct you to a sample Power of Attorney that might be helpful as a guideline. You can write your own Power of Attorney but the document has no legal standing until it is registered with the Office of the Public Guardian (£77 + VAT – everyone has to pay the fee to register a power of attorney).

Alternatively, most solicitors will draw up Powers of Attorney documents for around £350 to £400, including registration with the Office of the Public Guardian. The fee may include a visit to the person's home or residence to take instruction, drawing up the Powers, and returning to the home to get them signed and witnessed. If capacity is in doubt, the person with dementia will need a certificate from their GP.

Job centres will make copies of Power of Attorney, there is no charge. Just make sure each page has their official stamp and a clear hand written signature.

**Solicitors for Older People Scotland** (SOPS) is an affiliation of legal firms all over Scotland who will check first to see the person drawing up a Power of Attorney qualifies for legal aid. If not, check fees with individual solicitors.

People over the age of 60 years can also find a solicitor via SOPS. Go to – <http://www.solicitorsforolderpeoplescotland.co.uk/> or ring 0800 152 2037.

**Wills**, if not already done, should be written at this time as **a will cannot be written when capacity is lost**.

For help with accessing your **legal rights under Self Directed Support**, see information about the 3 R's Project in Section 5 below.

## 5. Getting support with caring

**Adult Carer Support Plan** (or Young Carer Statement for young carers under 18)

The **Carers (Scotland) Act 2016** came into being on **1 April 2018** – <http://www.carersnet.org/carers-act-resources/> **See also Section 1 above for more information.**

The Act is designed to support the health and wellbeing of carers, and places a duty on local authorities to provide support for carers. It replaces the previous carer assessment with an Adult Carer Support Plan which will identify care needs and personal outcomes.

The **Adult Carer Support Plan** will include information about:

- the personal circumstances of the carer
- the nature and extent of the care provided
- the impact on the carer's day to day life and wellbeing
- the extent the carer is able and willing to provide care
- the carer's personal outcomes and support needs
- the available support in the carer's local area
- whether support should be a break from caring
- whether the support meets the local eligibility criteria.

Each local authority is required to have an **information and advice service for carers** which should provide carers with information and advice on emergency and future care planning, advocacy and carers' rights (as well as income maximisation, education and training, health and wellbeing, and bereavement support for carers). They also have to publish their own **local carer's strategy** and, in addition, publish a **short breaks statement**.

Each integrated health and social care partnership has been charged with preparing to implement the Act in their local area. Contact your local Carers Centre for more information and advice about local arrangements.

## Self-Directed Support (SDS)

SDS is the approach to social care that gives you and your family choice about where, when and how you are supported by working out a budget that you use to buy the services that you need.

To get SDS, social services will assess the needs of the person you care for. If you can keep a record of daily needs or give examples of how you might use the support of a personal assistant, it will help social services construct a more realistic budget.

SDS encompasses four options:

- **Option One:** Direct Payment (using your budget to employ a Personal Assistant directly). This is the most cost effective option, but requires you to recruit and manage care input.
- **Option Two:** Individual Service Fund. Social services hold your Fund and you instruct them on what to book and whom to pay.
- **Option Three:** Arranged Service. Social services organise and pay for the support but consult you.
- **Option Four:** Combined Support. A combination of any, or all, of the above.

## SDS and the 3 R's Project (Rights, Respect, Responsibility)

This is a **legal rights** project, set up in 2017 and run by MECOPP. It assists individuals with social care support needs to realise new rights and entitlements conferred on them by the **Social Care (Self-directed Support) (Scotland) Act 2013**.

Funded in part by the Life Changes Trust, the project provides **specialist support to people with dementia and carers** – <https://www.mecopp.org.uk/3-rs-project>

The Project can provide advice and information on your legal rights under SDS, human rights and equalities legislation, undertake casework on your behalf to support resolution of more complex issues, and refer you to legal organisations if resolution cannot be reached.

You can self-refer directly, and a third sector organisation supporting you as an individual can also refer, anywhere in Scotland. You do not have to be a member of a minority ethnic community to access the project.

## Companionship Care

Attendance Allowance or Personal Independence Payment benefits might give you the option of booking one to three hours of companionship care from an agency such as Crossroads. To find your nearest office, go to – <http://www.crossroads-scotland.co.uk/contact>

## 6. Home adaptations and telecare

### Grab rails – free via social services and occupational therapy

Many local authorities will help to part fund wet rooms, but they will not finance chair lifts or rise and recline chairs for people with dementia or for people with Parkinson's related dementia.

**Care and Repair** provides independent advice and assistance to older and disabled people to enable them to stay in their own homes. Care and Repair operates in most local authority areas in Scotland. To find your local Care and Repair service, go to – <http://careandrepairsotland.co.uk/office-locations.html>

### Community alarms (if falls are an issue)

Some local authorities do not charge for community alarms if there is a diagnosis of dementia, but some do charge. Social services might also offer **Buddi Trackers** (a locator device worn on a lanyard, as a watch or like a mobile phone that enables carers to find people who are inclined to wander), **perimeter alarms** and **internal alarms**.

### Moving and handling

Take care of your back if, for example, you assist someone in and out of the bath or bed. Some occupational therapists or nurses will come out to the house to give carers tips on safe moving and handling. A **slide sheet** (a length of nylon material folded back on itself) is a very useful aid if you need to move someone up or down the bed. (Remember to remove it after using!).

## 7. Mobility

**Disabled parking permits** are also known as ‘Blue Badges’ – <https://www.mygov.scot/apply-blue-badge/>

The **Blue Badge** is awarded, based on physical mobility issues, for a fee of around £20. It is valid for a period of around three years. However, some local authorities are now offering a ‘cognitive impairment’ Blue Badge. Validity is limited to a year.

Scotland’s blue badge scheme for disabled parking has been extended to cover carers of people with dementia, autism and Down’s Syndrome.

**The cognitive process of getting in and out of a car can be quite complex for someone with dementia.** **Turn circles** are available to place on car seats as aids to help someone swing their legs into the car. The downside is that they don’t seem to work very well. An easier solution might be a sturdy black bin liner.

### The Motability Scheme

The Motability Scheme can help people who are disabled with leasing a car, powered wheelchair or scooter. Access is based on physical need. You will need to be in receipt of one of the following:

- higher rate of the mobility component of Disability Living Allowance (DLA)
- enhanced rate of the mobility component of Personal Independence Payment (PIP)
- War Pensioners’ Mobility Supplement (WPMS)
- Armed Forces Independence Payment (AFIP).
- Attendance Allowance cannot be used to lease a car through the Scheme.

There are two organisations which work together to deliver the Motability Scheme in the UK – the charity, Motability, and Motability Operations Ltd, a commercial company. Motability is responsible for the strategic direction and oversight of the Scheme, and Motability Operations Ltd, operates the Scheme under contract to Motability. See – <https://www.gov.uk/financial-help-disabled/vehicles-and-transport> and <https://www.motability.org.uk/>

**Wheelchairs** are free. Ask your GP for a referral. The British Red Cross also hires out wheelchairs for a donation to people who need one for short periods of time – <http://www.redcross.org.uk/What-we-do/Health-and-social-care/Independent-living/Mobility-aids>

## 8. Driving

**People with dementia are obliged to tell the Driver and Vehicle Licensing Agency (DVLA) if they wish to continue driving after they are diagnosed with dementia.** Anyone who fails to disclose a medical condition that might affect their driving could be liable to a £1,000 fine. If they fail to disclose and are involved in an accident, they might also be liable to prosecution. See – <https://www.gov.uk/dementia-and-driving>

## 9. Staying connected

### Playlist for Life

Music can be a wonderfully soothing influence for people with dementia. See – <http://www.playlistforlife.org.uk>

### Memory boxes and albums

As a carer, you are the person who knows all the likes, dislikes and funny family stories that make the person you care for unique. Start a family album or memory box of all the good times and encourage others to contribute. It provides a life-story in pictures that people with dementia can share – and one that is often fascinating for younger members of the family!

### The ‘twiddlemuff’

For people living with dementia who have restless fingers and cold hands. For instructions on how to make one, go to: [http://www.repod.org.uk/downloads/Twiddlemuffs\\_Instructions\\_24-01-15.pdf](http://www.repod.org.uk/downloads/Twiddlemuffs_Instructions_24-01-15.pdf).



## Day centre activities

If you are struggling with your caring commitments, look at the day centre activities for people with dementia available close to you, if the person you care for is happy to give them a try. There is often a range of activities on offer. Groups are aimed primarily at 65 years+ but not exclusively so.

There are Memory Groups, Musical Reminiscence and Sporting Groups (e.g. Football, Shinty, Bowling, etc). There are Dementia Walks, art classes and musical and choral groups that offer a caring and safe environment for the person with dementia so that you, the carer, can take a break.

In most instances, you can either self-refer, or ask for a referral from Social Services, Carers Centres or your Community Psychiatric Nurse. Depending on circumstances, you might be able to secure a place free of charge or you might have to pay a contribution to the cost.

**Try to keep yourself ‘connected’ too.** Ask your local Carers Centre or Local Authority about a **Carer’s Card** that might get you concessions, for example, reduced membership fees of leisure centres or discounts on theatre tickets. If you don’t ask, you don’t get! It isn’t demeaning to ask for discounts and you might pave the way for other carers.

## 10. Peer support for carers

If you would like to **meet other carers** for advice and support, contact:

### Carers Centres

To find your local carers centre, see – <https://www.mygov.scot/carers-centres/> or <https://careinfoscotland.scot/topics/support-for-carers/carers-centres/>

### Alzheimer Scotland

Alzheimer Scotland offer some services and groups for carers of people with dementia. Use their website search function to find out if there is a carer peer support service or group near you. See – <http://www.alzscot.org/search?q=carers+peer+support>

## Online support

If you struggle to get out of the house because of your caring commitment, you might need online support. **Talking Point**, Alzheimer's Society's online community for anyone affected by dementia, is an excellent online resource for carers. Carers register anonymously to participate in an online forum for practical advice from carers on anything and everything. See – <https://forum.alzheimers.org.uk/>. There are also Factsheets to inform carers about different aspects of dementia.

## Admiral Nurse Dementia Helpline – 0800 888 6678

The Admiral Nurse Dementia Helpline offers **specialist practical and emotional advice to families** caring for someone with dementia by **phone or email**. See – <https://www.dementiauk.org/get-support/admiral-nurse-dementia-helpline/>

The helpline is also available to people with a diagnosis of dementia, those worried about their memory or the memory of a loved one, and professionals working in dementia care.

The Dementia Helpline number is 0800 888 6678 or you can email [helpline@dementiauk.org](mailto:helpline@dementiauk.org). Its normal opening hours are 9am to 9pm from Monday to Friday and 9am to 5pm on Saturdays and Sundays.

Alzheimer Scotland – 24 Hour Dementia Helpline – Tel: 0808 808 3000

This is a 24 hour, freephone, Scottish service for people with dementia, carers, relatives, professionals, students and anyone concerned about dementia. It is confidential. You don't have to give your name if you prefer not to. It is staffed by trained volunteers, supported by a staff team at Alzheimer Scotland. Many have had personal or professional experience of caring for people with dementia.

## Peer to Peer Resources

The Life Changes Trust has provided funding to carers of someone with dementia, as well as people with dementia, to produce their own resources to raise awareness of a particular issue, offer advice or share learning that will help others (other people with dementia and/or carers). Go to <http://lifechangestrust.org.uk/projects/peer-peer-resources> and click on the section 'more information' to see resources produced to date and others currently in progress.

## 11. Respite, time out and creative breaks

Most carers find that, once the essentials are in place, life continues for some considerable time with just a few minor adjustments to accommodate their caring role. However, if you haven't been able to take a break at all for a while, consider:

### Creative break/time out funding

You can apply directly or ask your local Carers Centre or Alzheimer Scotland Resource Centre for a form. Your application will be put before a panel and you might be able to secure £300 to pay for a small break, or funding to develop a hobby or pastime, or to go on a spa break. The aim is to relieve the pressure on you as a carer.

Currently, if you are not getting any respite at all, every carer can apply twice in their caring 'career'.

If you need a break, or if you need medical treatment, you should ask social services for an assessment of the care needs of the person you care for in order to access funds to pay for **residential respite or live in care**, whichever is more appropriate.

All unpaid carers gained the right to fully funded respite when the Carers (Scotland) Act came into force in April 2018. However, it is each local authority's responsibility to publish a statement on short breaks and this will determine types of breaks and eligibility criteria.

## 12. Respitality

### Respitality (respite + hospitality)

This is a relatively new programme in Scotland. Companies in the leisure sector (e.g. hotels, spas, restaurants, tourist attractions, leisure centres) 'gift' tickets or short breaks to unpaid carers who haven't been able to take a break for some time or who are under acute stress.

Most local carers centres will be able to provide details of respitality breaks for carers or may even have their own respitality programme for local carers. Contact your local carers centre to find out more or call Shared Care Scotland on 01383 622 462.

## 13. Holidays

People living with dementia can often feel that holidays and travel are a thing of the past.

**Dementia Adventure** specialises in creating small group holidays for people living with dementia, their partners, family, friends or carer. See – <http://www.dementiaadventure.co.uk/holidays>

**Altogether Travel** is the UK's first supported travel company which holds care registration. They can plan, book and provide a holiday companion to look after your needs on the holiday of your choice. Ring 01236 222 006 or email – [info@altogethertravel.co.uk](mailto:info@altogethertravel.co.uk) or see – [www.altogethertravel.co.uk](http://www.altogethertravel.co.uk)

**Mind for You** offers supported holidays throughout the year for people living with dementia and their relatives/carers to enjoy together. See – [www.mindforyou.co.uk](http://www.mindforyou.co.uk)

## 14. Home design

**Dementia Services Development Centre (DSDC)**, based at the University of Stirling has a number of publications that offer '10 Helpful Hints' in caring for people with dementia. They also have a design centre aimed primarily at residential nursing homes but with useful ideas re layout, colours, clocks, lighting and alarms for people with dementia. See – <http://dementia.stir.ac.uk/>. To visit, contact DSDC on 01786 467 740.

## 15. Incontinence and urinary tract infections

**Incontinence (UTIs)** may occur later on in dementia, but not necessarily. If it is an issue for you, ask the District or Community Nurses attached to your GP practice for a referral to the Continence Service. The Service will write a prescription for pads (pants are not generally available on the NHS although some practices make an exception).

The pads will be delivered to you each month by courier. The service is free. Remember that weight gains and losses might require a different size of pad.

**Washable absorbent bed pads** (known as 'Kylie' sheets) are a good investment if you need to protect your mattress, but they are not available on the NHS. You can buy them online – for example, Amazon and eBay are good places to compare prices.

Men with dementia sometimes struggle to differentiate a white seat from the toilet bowl. Encourage sitting rather than standing, if possible. **Red toilet seats** make the toilet easier to see.

**Pet shops** are a useful source for sprays that neutralise odour.

**UTIs** occur mainly because people with dementia do not drink enough fluid. Tea and coffee are diuretics so it is better to prompt with water or diluting juice or fruit juices diluted with water. UTIs present with increased confusion, 'gobbledegook', and urine with a strong smell and a dark colour. If UTIs are caught early, they are easily treated with antibiotics.

## 16. Pain

Pain, like depression, is often untreated in dementia but it need not be. As a carer, you can probably identify pain signals very easily. Palliative care in the community is via GP referral.

**Palliative care is NOT solely for end of life care.** Palliative care was redefined by the World Health Organisation (WHO) to be pain relief for anyone suffering with a long term, degenerative condition.

## 17. Medication –difficulty swallowing pills

If you are finding the person with dementia is finding it difficult to take their pills, and are facing this dilemma, you may well want to look first at this helpful guidance – 'Good Practice Guide – Covert Medication' produced by the Mental Welfare Foundation for Scotland – <https://www.mwcscot.org.uk/publications/good-practice-guides/>

The guidance talks about 'covert medication' and defines it as '...the administration of any medical treatment in disguised form. This usually involves disguising medication by administering it in food and drink. As a result, the individual is unknowingly taking medication. This is likely to be due to a refusal to take medication when it is offered, but where treatment is necessary for the individual's physical or mental health.'

## 18. Going missing

This is about **thinking ahead and being prepared**. It may never be needed but, if the person you care for does go missing, you can **save valuable time** in a situation which can be very distressing and stressful for them and for you.

While the common focus by the police and other services is on finding the missing person, currently, the approach to finding someone who has gone missing, including people with dementia, can vary across Scotland. The first thing may be to **contact your local police and find out about the local procedure**.

Ask about:

- what **key information your local police need to have**, if the person you care for does go missing, to speed up and simplify the response. For example, this might include a recent photo and their physical description, their routines and significant places, up to date medical details of any condition they have and the consequences if they do not have medication, next of kind details, Power of Attorney or Guardianship arrangements, and details of cash or bank cards they have access to.
- **what you can put in place now and how to do it** – for example, how you can prepare this information now and ensure it is held in a way that is **secure but accessible**, to be made available to the police as soon as possible if needed.

Scotland's first **National Missing Persons Framework** was launched in May 2017 to help prevent people from going missing in the first place and to ensure they receive the best possible support when they do. It highlights good practice and brings more national consistency to help achieve standardised responses locally when someone goes missing. See – <https://www.gov.scot/publications/national-missing-persons-framework-scotland/>

An update was published in May 2018, detailing progress and priorities for the future. See – <https://www.gov.scot/publications/missing-persons-framework-update-report/>

## Purple Alert

This is a free, community-minded app that is helping people look out for their neighbours. It was designed by people living with dementia and carers, Alzheimer Scotland staff, Police Scotland, social work, Dementia Friends Scotland, health and social care partnerships and telecare services.

With the support of people living with dementia and their carers, Police Scotland and health and social care providers have developed the Purple Alert app as a way to help find people.

The app allows carers to share the person living with dementia's profile if they lose their way and allows for eyes and ears on the ground immediately helping to find them.

Purple Alert is the first app of its kind in the UK and it is available for free download to iOS and Android smartphones. For more information and to download the app, go to: <http://purplealert.org.uk/>

## 20. Transition to residential or nursing care

**Knowing when you cannot continue to care**, because it is not safe for you or not safe for the person you care for, is one of the most painful decisions that carers face.

**Choosing a good care home and understanding the financial assessment process** can be daunting. Age Scotland has excellent publications regarding the process. It also has a small checklist booklet giving tips on what to look out for when you visit prospective homes. See – <https://www.ageuk.org.uk/scotland/information-advice/care-and-support/care-homes/>

Your local Carers Centre may hold **information sessions on choosing care homes** and how to handle the transition – and you will meet other carers going through the same process.

**The caring doesn't stop** when the person you love moves to a care home. It might give you the chance to be less of a carer and to be more of a wife, a husband, a daughter or son if someone else takes on the practical management of care.

## Letting go and staying involved

Alzheimer Scotland's booklet **Letting Go Without Giving Up** is aimed at carers who want to continue their involvement in the life of the person they have cared for, even if they are no longer responsible on a day-to-day basis. See – [http://www.alzscot.org/information\\_and\\_resources/information\\_sheet/1828\\_end\\_stage\\_dementia\\_letting\\_go\\_without\\_giving\\_up](http://www.alzscot.org/information_and_resources/information_sheet/1828_end_stage_dementia_letting_go_without_giving_up)

## Making the most of visits

It can take some time to come to a good understanding of what makes a good visit when you go see your loved one living in residential care.

**Come On In** is a guide written by the Care Inspectorate and Campbell Snowdon Care Home to help friends and family of people living in care homes make the most of their visit. Go to – <http://www.lifechangestrust.org.uk/people-affected-by-dementia/come>

## Getting in touch

If you have any queries or wish to share your views and ideas, you can contact the Life Changes Trust in a number of ways:

Phone: 0141 212 9600

Email: [enquiries@lifechangestrust.org.uk](mailto:enquiries@lifechangestrust.org.uk)

Website: [www.lifechangestrust.org.uk](http://www.lifechangestrust.org.uk)

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199 Sauchiehall Street, Glasgow, G2 3EX



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Registered in Glasgow, Scotland  
Registered Charity Number SC043735  
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Registered Charity: SC043816