

Dementia: the Carer's Experience

Better Enabled, Better Equipped

A Dementia Checklist

A Resource by Carers for Carers

September 2017



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Foreword

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

Acknowledgements

Along with Katharyn Barnett, as the initiator, other contributors to the Dementia Checklist are:

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Maureen McKillop

Bernard O'Hagan

Anne Rankin

Annette Tait

Katharyn, Myra, Maureen, Bernard, Anne and Annette have long experience of caring for someone with dementia, unpaid. The Dementia Checklist is their work.

Dementia – A Carers Local Directory has also been produced by the steering group in the first instance for carers attending the group's first conference, **Dementia: the Carer's Experience**, on 30 September 2017 in Glasgow.

The Dementia Checklist and the Directory - both produced for the conference - 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.

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 invited these six carers to form a steering group, supported and funded by the Trust, to come together to plan and organise as they saw fit an event, or a series of events, for carers. The group first met in January 2017. **By carers for carers** has been the enduring theme of their hard work over the past nine months.

The **Dementia Checklist** has been produced by the steering group in the first instance to give to carers attending the group's first conference, '**Dementia: the Carer's Experience**', on 30 September 2017 in Glasgow.

Carers Conference Steering Group

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1. Money Matters

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: £55 per week and £83 per week for those whose needs are more severe. Age Scotland has an excellent booklet that explains eligibility criteria.

- To claim: you can download Attendance Allowance forms and complete them yourself or you might prefer to contact the 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.

Carers Allowance

Carers Allowance is paid at a rate of £62 per week 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 Carers Allowance. Carers who earn over £110 a week or who receive a state pension are not awarded Carers Allowance. If you claim, the Department for Work and Pensions might reduce the sum awarded to the person you care for.

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 25-50% 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/>

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.

2. 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.

3. 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 (£73 + VAT).

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 includes 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.

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, the fee is £323.80 (£455 for two Powers drawn up at the same time e.g. for husband and wife).

People over the age of 60 years can also find a solicitor via SOPS:

<http://www.solicitorsforolderpeoplescotland.co.uk/>

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 4 below.

4. Getting Support with Caring

Carer Assessment/Carer Support Plan

Currently, Local Authorities have a duty to assess a carer's ability to care through an assessment and have the power to provide support where necessary. NHS Boards can also be required to publish a Carer Information Strategy setting out how carers will be informed on their right to request an assessment.

The Carers (Scotland) Act 2016 will come into being on 1 April 2018 - <http://www.carersnet.org/wp-content/uploads/2014/06/Carers-Scotland-Bill-Briefing.pdf>. The Act is designed to support the health and wellbeing of carers by placing a duty on Local Authorities to provide support for carers. It will replace the current 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 will require to have an **information and advice service for carers** which should provide them with information and advice to carers 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).

Currently, Integrated Health and Social Care Partnerships are preparing the way for the implementation of the Act.

Until then, all carers have the right to a carer assessment, which can be requested from your GP or social worker if the person you care for is receiving social care.

Self Directed Support (SDS)

SDS is a new 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.,
Respect, Responsibility

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

This is a new **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** - http://www.mecopp.org.uk/services-new__the_3_r__s_project.php?section_id=396

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>

5. Home Adaptations and Telecare

Grab rails are 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.

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!).

6. 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.

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.

Motability cars are based on physical need but are only available to people under the age of 65 years.

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>

7. 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.

Go to <https://www.gov.uk/dementia-and-driving>

8. 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. Go to - http://www.repod.org.uk/downloads/Twiddlemuffs_Instructions_24-01-15.pdf - for instructions on how to make one.



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.

9. Peer Support for Carers

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

Carers Centres

For your local Carers Centre, see the local directory in your conference delegate pack.

Alzheimer Scotland

Alzheimer Scotland offer some services and groups for carers of people with dementia - <http://www.alzscot.org/search?q=carers+peer+support>

Use their website search function to find out if there is a carer peer support service or group near you.

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. <https://forum.alzheimers.org.uk/>. There are also Factsheets to inform carers about different aspects of dementia.

Admiral Nurse Dementia Helpline

The Admiral Nurse Dementia Helpline offers **specialist practical and emotional advice to families** caring for someone with dementia by **phone or email** - <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. Its normal opening hours are 9am to 9pm from Monday to Friday and 9am to 5pm on Saturdays and Sundays.

Currently in **Scotland**, Admiral Nurses provide a service in Glasgow - the **Glasgow Admiral Nurse Service with BUPA. BUPA work with people living with dementia within BUPA care homes and their carers**. Community services, dependent on resources, may be available for non BUPA clients. To contact the Glasgow service directly, call 0141 880 8040. See <https://www.dementiauk.org/get-support/find-an-admiral-nurse/>

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.

10. 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 will have the right to fully funded respite when the Carers (Scotland) Act comes into force in April 2018. However, it is Local Authorities which will determine eligibility criteria.

11. Respitality

Respitality (respite + hospitality) 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.

12. 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 - <http://www.dementiaadventure.co.uk/holidays>

13. 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 Lynsey Manson on 01786 467 732.

14. 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.

15. 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 (EOLC). Palliative care was redefined by the World Health Organisation (WHO) to be pain relief for anyone suffering with a long term, degenerative condition.

16. 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.

Since 2015, Police Scotland together with others (for example, local authorities), have been running pilots in three areas. They are looking at ways to safeguard people considered at risk of going missing and to prevent this, as well as ways to respond which ensure people are found safe and well. According to the **National Missing Persons Framework for Scotland** published in May 2017, the results and learning will be available in May 2018 and used to help achieve standardised responses and best practice - <https://beta.gov.scot/publications/national-missing-persons-framework-scotland/pages/8/>

17. 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 <http://www.ageuk.org.uk/scotland/home-care/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 - 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

Website: www.lifechangestrust.org.uk

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