

# A Road Less Rocky

## Making the Road Less Rocky for Carers

A Guide on how to Support Carers  
of People with Dementia





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# Acknowledgements

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# Contents

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	<b>Introduction</b>	<b>2</b>
<b>1</b>	<b>When dementia is diagnosed</b>	<b>3</b>
<b>2</b>	<b>When the carer takes an active caring role</b>	<b>5</b>
<b>3</b>	<b>When the capacity of the person with dementia declines</b>	<b>8</b>
<b>4</b>	<b>When the carer needs emotional support</b>	<b>11</b>
<b>5</b>	<b>When the person with dementia loses mobility</b>	<b>14</b>
<b>6</b>	<b>When the person with dementia has other health problems</b>	<b>16</b>
<b>7</b>	<b>When the carer has to cope with behaviour problems</b>	<b>18</b>
<b>8</b>	<b>When the carer's own circumstances change</b>	<b>20</b>
<b>9</b>	<b>When the person with dementia becomes incontinent</b>	<b>22</b>
<b>10</b>	<b>When decisions about residential care and end of life care have to be made</b>	<b>24</b>
	<b>Useful contacts</b>	<b>27</b>
	<b>References</b>	<b>30</b>

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# Introduction

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A Road Less Rocky – Supporting Carers of People with Dementia (Newbronner, L et al, 2013) is research commissioned by Carers Trust, to understand more about the journey undertaken by carers of people with dementia. The research found that although there is no ‘typical caring journey’ there are ten critical points where, if the appropriate support and advice had been given, the experience of caring for someone with dementia would have been made a little easier.

This toolkit is designed around these ten points; the issues carers face at these points and what will make a positive difference. This resource complements the more extensive toolkit found on <https://professionals.carers.org/supporting-carers-people-dementia>.

The toolkit is useful for anyone who works with or treats patients with dementia and is therefore likely to come into contact with carers. Particular critical points are more relevant to certain services.

A Road Less Rocky – Supporting Carers Of People with Dementia, complements, The Triangle of Care: Carers Included: A Guide to best Practice for Dementia Care (Carers Trust, 2013).

Carers Trust’s Triangle of Care programme has been running in England since 2010. It aims to ensure carers can access support when the person they care for is admitted to mental health services and encourages joined up working between the carer, service user and professionals. The Triangle of Care is now being developed in Scotland and Wales.

The Triangle of Care guide describes how meaningful involvement and inclusion of carers can lead to better care for people with dementia. The guide identifies six key standards required to achieve better collaboration and partnership with carers.

Although the terminology and legislation referred to in this guide applies to England the standards and rationale are applicable across the whole of the UK.

## About Carers Trust

Carers Trust is a major new charity for, with and about carers. We work to improve support, services and recognition for anyone living with the challenges of caring, **unpaid**, for a family member or friend who is ill, frail, disabled or has mental health or addiction problems.

We do this with Network Partners – a unique network of 116 independent carers centres, 55 Crossroads Care schemes and 99 young carers services. Together we are united by a shared vision for carers – to make sure that quality assured information, advice and practical support are available to all carers across the UK.

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# 1

## When dementia is diagnosed

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“Carers and staff have so much to learn from one another – they need to work together to get the best for the person who has dementia.”<sup>1</sup>

### Carer engagement – listening to carers’ needs

Professionals, particularly GPs, can benefit from listening to and taking account of carers’ concerns. Carers are experts by experience when it comes to the person they care for, therefore valuable information about the person with dementia can be obtained through consulting them, it is also imperative to listen to any concerns they have about their own health.

If carers are offered information about the types of dementia, and its possible progress at this early stage it can help them plan for the future, understand the person they care for and plan for their needs. Remember that although the person with dementia may not always want to know what the future holds, it is very important for the carer to be able to plan.

### Timely diagnosis is vital

Receiving a diagnosis in good time is vital, even though it can be traumatic. It can open doors to much needed services, treatment and extra finances. Timely diagnosis can also give the person with dementia and their carer more time to plan for the future. For the carer it also gives an explanation to the behaviour changes they have noticed in their family member or friend.

### Access to specialist multi-disciplinary teams

NHS services often take for granted that patients and carers understand their systems and procedures, however giving clear information on referral routes and what those services do is important for carers and patients. Carers report they have often come away from an initial appointment in shock and unaware of how to get back in touch, or where to go for further support. Carers value both professional and peer support and at this stage are particularly interested in help and support with the cognitive difficulties in the person with dementia.

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<sup>1</sup> All the information and quotes, except where referenced, have come from Newbronner, L et al, 2013.

Carers should be offered information or a referral to local carers and dementia services even at this early stage, they will be able to help them come to terms with the diagnosis, understand the present and plan for the future.

## Advice and information about dementia-related medication

Carers can benefit from advice and information about dementia-related medication (and, where appropriate, interactions with other medications). Medication is a real concern for carers as they are commonly the one who takes on the responsibility for medicines management. It is important where possible to include carers in the conversation about choices of medication, likely success and any side effects. Carers can then have further discussions with the person they care for and be on the lookout for any side effects.

Carers can be directed to local pharmacies, pharmacy helplines, and helpful websites for more information.

### Further information

#### **What is dementia?**

See [www.alzheimers.org.uk](http://www.alzheimers.org.uk)

#### **Support for carers from Admiral Nurses**

See [www.dementiauk.org](http://www.dementiauk.org)

#### **Working with carers**

See [www.rcpsych.ac.uk](http://www.rcpsych.ac.uk)

#### **Find local carers services**

See [www.carers.org](http://www.carers.org)

#### **How pharmacy services can help**

See [www.nhs.uk](http://www.nhs.uk)

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# 2

## When the carer takes an active caring role

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“Lifting and handling would be really useful to learn about. Still don't know if I am doing it properly.”

Dementia is a complex, unpredictable condition, and as the disease progresses close relatives and friends find themselves offering an increasing amount of support to enable the person with dementia manage everyday life. The carer will find themselves adjusting their lives to accommodate these extra demands.

### Information about dementia – its impact and progression

A significant number of carers have reported that they do not understand what a diagnosis of dementia can mean, and the impact it can have. Carers need to be prepared and able to plan for the future and can only do this if they have the relevant information about the possible impact and progression of the disease.

### Develop an information checklist for professionals

Carers are all very different and have their own needs and pressures, it is often too easy to assume carers will ask if they need advice and support or know how to access information. A checklist designed for professionals would help ensure important issues are not missed. A good checklist would include UK wide and local information.

### Signposting to local and UK wide information sources about dementia

Taking on an active caring role for someone with dementia can be a daunting and stressful prospect. Carers often feel isolated; with carers of people with dementia experiencing the added problem of stigma. Having contact with UK wide and local organisations for support is invaluable.

Not all carers will be in a position to refer themselves to the relevant organisations, in fact it is often those who most need the support who do not have the time or strength to look for it. Getting permission from the carer and making a referral could prevent carers falling into crisis. Talk to your local carers service about setting up a simple referral system, they will be more than happy to help.

## Advice about legal issues

Advice about legal issues and financial support for people with dementia and carers is vital. Many carers are not informed of the need for a lasting power of attorney until the person they care for has lost the capacity to make informed decisions about the future or until there is the need for residential care.

Carers have advised how important it is to receive information about lasting power of attorney, advance decisions and advance statements at the earliest possible time. Ensuring that these actions are taken at the earliest possible time provides carers with piece of mind (and sometimes financial security) and ensures the wishes of the person with dementia are respected. If not done, this can have serious consequences when making important decisions about medical treatment and interventions.

Caring for someone with dementia can be expensive, and have a serious impact on the family income. People with dementia and their carers may have to give up work, and probably need to spend more money on transport, heating, adaptations and replacement care. It is important that families have a benefits check by a trained advisor to ensure they receive the help they are entitled to.

## Information about support available and key contacts for the future

Carers advised that it is important they know how and where to get the right support when they need it. Ideally this would be from one person, or more realistically one place or central contact. This could be your local carers service.

A card or factsheet for carers with useful contact numbers can be beneficial, it is important however to ensure the information is up to date.

## A timely carer's assessment

The Care Act in England provides parity for carers with those they care for. Ideally, both should have their needs assessed, along with those of other family members at the same time. There are separate laws about social care in Wales, Scotland and Northern Ireland.

If the person with dementia refuses an assessment or a service this does not mean the carer is excluded from receiving support. Carers have their own rights including the right to a carer's assessment and services.

It is always important to review the carer's assessment as dementia is a progressive and sometimes unpredictable condition, creating stress points for the carer as the disease progresses. The carer's own circumstances can also change, and they may have concerns about their own health, employment or financial situation.

## Further information

### **How the Care Act affects carers in England**

See [www.nhs.uk](http://www.nhs.uk)

### **Carers rights guides**

See [www.carersuk.org/help-and-advice/get-resources/carers-rights-guide](http://www.carersuk.org/help-and-advice/get-resources/carers-rights-guide)

### **Disability and carers benefits and entitlements**

See [www.gov.uk/browse/benefits/disability](http://www.gov.uk/browse/benefits/disability)

### **Order a free dementia guide from Alzheimer's society**

See [www.alzheimers.org.uk](http://www.alzheimers.org.uk)

### **Find local carers services**

See [www.carers.org](http://www.carers.org)

### **Find local dementia services**

See [www.alzheimers.org.uk](http://www.alzheimers.org.uk)

### **Information on lasting power of attorney, advance decisions and advance directives**

See <http://compassionindying.org.uk/making-decisions-and-planning-your-care/planning-ahead/lpa-or-advance-decision/>

### **Professional support, who they are and what they do**

See [www.dementiacare.org.uk](http://www.dementiacare.org.uk)

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# 3

## When the capacity of the person with dementia declines

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“ Although I had the contact details for Carers Trust it took me a long time to finally admit that I was not coping as well as I thought I was. ”

### Repeated or topped up information and advice

Professionals who come into contact with carers and people with dementia can check they have all the relevant information they need at this time. Dementia is a progressive condition with people typically living between 7–12 years after diagnosis. The need for information and support is high each time the person with dementia progresses into a new phase of the illness.

Ask the carer and the person with dementia if someone has discussed lasting power of attorney and advance statements (or living wills) with them. Ensure they are provided with the support to access lasting power of attorney, advance statements and decisions. Ideally, this should happen as early in the caring journey as possible, before the person with dementia's capacity declines. If this has started to happen, ensure this is actioned as early as possible.

Ensure carers have the right information to understand the implications for them about the deterioration of capacity in relation to making decisions on health, finance and social care.

Local carers services will be able to give information about local training programmes and support groups where carers can access information and support.

### Ongoing support or contact with a mental health worker and support and advice from a social worker

Ongoing support doesn't necessarily have to be frequent, however carers have stressed how important consistent support is. Carers can feel reassured if they have a point of contact for further support if needed, and are actively encouraged to use it.

Carers value expert advice on strategies for caring for someone with dementia and will benefit from being able to top up this knowledge as the dementia progresses. Regular monitoring of the person with dementia can help highlight emerging support needs, allow for any adjustments in medication and monitor the carer's ability or desire to care.

## Information and easy access to a community care assessment of the person with dementia and a carer's assessment for the carer

An assessment for the carer and the person with dementia should be reviewed regularly and include questions about the carer's ability or willingness to continue to care.

Dementia is a complex, unpredictable and progressive illness. As the disease progresses and carers become increasingly concerned about the safety of the person they are caring for, their input will increase and become more demanding. Carers may no longer feel confident to leave the person with dementia on their own. Some carers may also find they are no longer willing or able to continue in their caring role. A good quality carer's assessment, where the carer's needs and wishes are acknowledged, should highlight these issues and help plan the relevant support for the carer and the person with dementia.

The more demanding the caring role, the more important it is that carers receive support which may include the need for regular respite. Respite can come in many different forms from a few hours weekly, to longer one off breaks. The break is primarily for the carer, although the person with dementia may also benefit. Support to access social care services will help reduce any further stress on the carer.

Carers require information regarding eligibility for social care services for them and the person with dementia, what support is available locally, how much it will cost and when and how much they may need.

## Personal care at home provided by a small group of care workers who are trained to care for people with dementia

For carers to feel confident about accepting help with care or taking a break they need to feel reassured about the quality of replacement care. People with dementia have very specific needs and are particularly sensitive to change, often responding badly to new people and environments. Having information early on will give the carer and the person with dementia the opportunity to explore different care settings.

## Recognition in assessments of the importance of practical support in the home

Carers find that as well as managing the routine health and care needs of the person with dementia they increasingly take on the practical and administrative tasks around the home. Keeping on top of these tasks, particularly laundry if the person is incontinent can be exhausting and time consuming, and outside help can be expensive to purchase. Carers who are not living with the person they care for, find in effect they are managing two households. Recognition of these tasks during the carer's assessment can give a more holistic picture of the carer's role and which services would help manage the situation.

## Positive advice about coping with dementia

It is important to carers that they feel confident about the care they are giving. Carers value advice on strategies for communication, stimulation, setting routines and making the home dementia friendly. Carers will also benefit greatly from positive advice and coping strategies around their own physical and mental wellbeing.

The research for A Road Less Rocky found that carers who received training gained confidence, felt more empowered and became more assertive. Some local carers services offer training programmes for carers some of which are dementia specific.

### Further information

#### **Advance decisions and advance statements explained**

See [www.ageuk.org.uk](http://www.ageuk.org.uk)

#### **Choosing the right daily living equipment**

See [www.dlf.org.uk/content/full-list-factsheets](http://www.dlf.org.uk/content/full-list-factsheets)

#### **Equipping yourself to help with forgetfulness**

See [www.fastuk.org](http://www.fastuk.org)

#### **Making the home dementia friendly**

See [www.dementiacare.org.uk](http://www.dementiacare.org.uk)

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# 4

## When the carer needs emotional support

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“ [If we had known] earlier in her diagnosis, we could have explored support networks and taken advantage of them.”

### Support groups

For some carers, having a break and accessing emotional support does not mean time away from the person they are caring for. For some, having a break and meeting people together with the person they care for is preferential as it is a continuation of their everyday life, other carers may feel too anxious to leave the person with dementia.

People with dementia can become disorientated and frightened in strange places and among people they don't recognise. Having a break together with the person they care for or visiting a dementia cafe for emotional support can be the stepping stone for some carers to taking a break on their own. Peer support groups and training sessions can be invaluable to carers, ensuring they feel less isolated. At these sessions carers will meet others who share the same difficult practicalities and emotions. Contact your local carers service for information on support for carers.

### Active signposting to carers support services

A number of carers interviewed for A Road Less Rocky said they wished they had known about various support services earlier. Carers are a diverse group of people and will prefer to access support in different ways, ranging from local support groups and UK wide and local helplines, to online support. It is important to give carers information on how to access local and UK wide organisations at the earliest possible opportunity. They may not make contact immediately, but the information is a reminder that support is there if needed, and may prevent a future crisis.

### Professionals recognising when carers need emotional support

Carers can find it difficult to accept emotional support, yet it is extremely important for their health and wellbeing. Professionals can play an important role in encouraging or facilitating carers to receive the right support in good time. Emotional support can come from a variety of sources – family and friends, professional counselling, carers groups and other services. Emotional support can

be particularly important at some of the critical points, for example when the person with dementia loses capacity, becomes incontinent or residential care is being considered.

## Helping carers plan time off from caring

Having a break from caring is vital if carers are to maintain their emotional and physical wellbeing. Carers may need encouragement and support to take a break, if they have not done so before. The break should primarily meet the need of the carer, although it may also benefit the person with dementia.

Due to the nature of dementia, it is preferable that any respite is introduced gradually and before capacity declines, allowing both the carer and person with dementia to become familiar and confident with the arrangements.

Carers who do not live with the person they care for are often overlooked when it comes to needing a break, yet are often working, bringing up a family and effectively managing two homes. It is important to consider the needs of all carers involved and provide personalised support.

## Respite information

Respite can take many different forms and it is important that carers have good information about the choices available to them locally and the possible costs. This will allow them to make an informed decision on what will work best for them and the person they care for. Carers value professional support when having to make difficult decisions around care arrangements and taking a break, it is not uncommon for carers to feel unnecessarily guilty about having time off. This support is valued regardless of whether people are full cost payers, fully funded or make a contribution. It is important to incorporate respite plans as early as possible into care plans rather than waiting until a crisis necessitates it.

## Support for carers to maintain lifestyle choices

Carers often find themselves having to give up work due to their caring role, this can have a detrimental effect on their health, finances and future career. If carers and their employers are aware of legal entitlements as well as wider support, carers can remain in work for longer. Carers have the right to request flexible working and time off under the Work & families Act 2006 and are protected against discrimination at work under the Equality Act 2010.

A carer's assessment is a good tool for carers and professionals to use when considering the support needed for carers to balance caring, work, family and other community commitments. Working or volunteering is a valuable respite from caring, and can help towards sustaining carers in their role.

## Further information

### **Find local carers services**

See [www.carers.org](http://www.carers.org)

### **Find local dementia services**

See [www.alzheimers.org.uk](http://www.alzheimers.org.uk)

### **Tips on how to manage as a carer**

See [www.mind.org.uk](http://www.mind.org.uk)

### **Buying in care**

See [www.carers.org/help-directory/buying-care-questions-carers-and-family-members-should-ask](http://www.carers.org/help-directory/buying-care-questions-carers-and-family-members-should-ask)

### **Options for respite care**

See [www.alzheimers.org.uk](http://www.alzheimers.org.uk)

### **Carers' employment rights**

See [www.carers.org/help-directory/right-flexible-working](http://www.carers.org/help-directory/right-flexible-working)

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# 5

## When the person with dementia loses their mobility

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“ I hurt my back lifting him when I should have said no but he was shouting that I didn't care and he needed help so I gave in. ”

### Preparing carers for loss of mobility

Information, advice and practical training to safely move and transfer people is key to ensuring the health and safety of carers and the person they care for. Timely access to equipment and training is essential for carers as a physical injury could have a huge impact on the carer's willingness or ability to carry on caring at home.

There are some health and safety measures that have no or very little cost, for example removing trip hazards, ensuring the house is well lit, and using timers for electrical items. The longer carers have to plan for adaptations the easier it will be to make the necessary adjustments in the home and for the person with dementia to become accustomed to them.

Transport, especially in more rural areas of the country, can be a real issue for carers of people with dementia. Good information about UK wide and local transport services for disabled people will help to ensure carers and the people they care for continue to access activities, visit friends and family and attend necessary appointments.

### Advice on equipment and adaptations

Early information and advice on equipment for the home can prevent a risk becoming a serious accident. Smaller pieces of safety equipment can be invaluable when it comes to health and safety in the home. Information on telecare services, gas and water safety devices and home fire safety checks can give carers some reassurance.

Equipment and adaptations can be very expensive and are not always funded by the local authority. There are a number of local and UK wide charities which can lend assistance, many of the funds cover specific localities or vocations. Some organisations require a professional to make the application on behalf of the person, but not all.

## Advice and training for carers in lifting and handling

As the mobility of the person with dementia declines, carers find themselves giving increased manual assistance and may not be aware they are putting themselves at risk of injury. Carers need advice and training in good time, to prevent either a gradual or sudden deterioration of their health. A number of carers services offer training for carers which will often include a session on moving and handling as well as general back care.

If equipment such as slide sheets and hoists are supplied, it is important the carer receives training on their safe use.

In situations where care staff are going into the home, carers will still need advice and training, as they often double up with the care staff, and may assist the person with dementia when care staff are not available.

### Further information

#### **Find local carers services**

See [www.carers.org](http://www.carers.org)

#### **Making the home dementia friendly**

See [www.dementiacare.org.uk](http://www.dementiacare.org.uk)

#### **Adapting your home for someone with a disability**

See [www.ageuk.org.uk](http://www.ageuk.org.uk)

#### **Blue Badge scheme**

See [www.gov.uk/blue-badge-scheme-information-council](http://www.gov.uk/blue-badge-scheme-information-council)

#### **Applying to a charitable fund**

See [www.turn2us.org.uk](http://www.turn2us.org.uk)

#### **Information about assistive technology**

See [www.alzheimers.org.uk](http://www.alzheimers.org.uk)

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# 6

## When the person with dementia has other health problems

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“ [I would have liked] someone to support me and advise on how to deal with certain situations – particularly with cancer diagnosis and not knowing how to speak to Mum about it or at all as she would soon forget anyway. I found myself having to speak to medical staff before any appointments to ensure they knew she had dementia. ”

### Recognition of carers' role

It is possible that carers will come into contact with health professionals because of health conditions both associated with and independent of dementia. You should not assume that the carer has already been identified and given all the information they need, or a referral made to carers support services. Carers quite often do not recognise their role and can fall through the net. Recognising the role opens up the opportunity to check how the carer is managing day to day. Due to the progressive nature of dementia, carers will find themselves increasingly taking responsibility for healthcare tasks including nutrition, hydration and medication and in the later stages skin care, so value good information and advice in these sometimes complex areas.

If the person with dementia is admitted into hospital, carer involvement is fundamental to good care delivery. Carers need to be involved in any decisions and kept informed at all stages particularly at discharge planning and end of life care. The Triangle of Care can help health services achieve better collaboration between the clinician, carer and the person with dementia.

### Holistic healthcare support

Having access to regular health checks can help pick up any health problems which may make the dementia appear worse and put extra strain on the carer. Carers interviewed for A Road Less Rocky reported that it was often health conditions

unrelated to the dementia which triggered unscheduled reviews or hospital admission.

Because the majority of people diagnosed with dementia are over 65 there is an increased chance of co-morbidity, which can complicate the support carers provide, for example maintaining dietary requirements for someone who also has diabetes.

Carers are often experts by experience in relation to the person they care for and can give valuable insight to any changes in behaviour and appearance. Dementia is a degenerative condition which can affect insight. By listening to carers' concerns, health problems can be addressed and treated early before they deteriorate.

## Information about NHS continuing healthcare

NHS continuing healthcare is healthcare delivered outside of hospital that is arranged and funded by the NHS. Access to information and advice on all types of care options, eligibility criteria, and how to make an application will give carers the confidence to request the right type of replacement care at the right time.

If NHS continuing healthcare is being considered, carers and the person with dementia (if possible) will benefit from being involved in the process. Because the application process is complex, carers may benefit from expert advocacy support.

### Further information

#### **Help with NHS continuing healthcare**

See [www.ageuk.org.uk](http://www.ageuk.org.uk)

#### **Information for people caring for someone with dementia**

See [www.dementiacare.org.uk](http://www.dementiacare.org.uk)

#### **Triangle of Care working with dementia carers**

See [www.rcn.org.uk](http://www.rcn.org.uk)

#### **Help with managing pain**

See [www.paincentrenapp.co.uk](http://www.paincentrenapp.co.uk)

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# 7

## When the carer has to cope with behaviour problems

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“ I loved my mum more than words can ever express but dementia could turn her and me into monsters that I didn't recognise. ”

### Information about changes in behaviour and positive strategies for dealing with them

Behaviour changes are a major issue for carers of people with dementia – as the dementia progresses new and more difficult behaviours can emerge. Ongoing information, advice and training is important to enable carers to put strategies in place to improve the situation. In addition, recognising the emotional impact these behaviour changes can have on carers and ensuring carers have the opportunity to talk about them is crucial.

Some carers will prefer to be equipped early on for any possible behaviour change, where others will prefer to receive information as and when behaviour starts to change.

Identifying common behaviour problems, sundowning for example and preparing carers for these may prevent carer breakdown.

### Advice and support in managing changing behaviour

In the latter stages of dementia carers can find themselves ill-equipped to deal with agitated and aggressive behaviours that can develop (including difficult sexual behaviour), and carers may feel embarrassed, angry or frightened. Carers say they value support, advice and information from professionals on how to manage these issues, and keep themselves and the person with dementia safe.

Carers can be fearful and embarrassed to bring up the subject of difficult behaviours, wrongly assuming they will be judged badly if they are not managing. Professionals can therefore play an important role by approaching the subject and reassuring the carer, offering strategies, extra support and referring to training or support groups.

## Information about night care

Providing care at night and having to manage frequent night time disturbances can leave carers exhausted, making it more difficult to cope generally. Professionals can help by exploring the options for night time services with carers, such as using personal budgets and NHS continuing healthcare to fund support or, in some areas accessing Admiral Nurses.

Caring for someone with dementia can be a long-term task and for carers to continue caring at home they need to be able to keep themselves well. Disturbed nights will inevitably put extra pressure on a carer's health and wellbeing and without support may result in a crisis or breakdown in the caring relationship.

### Further information

#### **Strategies to help with managing changes in personality and behaviour**

See [www.alzheimers.org.uk](http://www.alzheimers.org.uk)

#### **Strategies to help with managing sleeping patterns and sundowning**

See [www.alzheimers.org.uk](http://www.alzheimers.org.uk)

#### **Drug treatments and dementia**

See [www.alzheimers.org.uk](http://www.alzheimers.org.uk)

#### **Professionals – what they can do and how they can help**

See [www.dementiacare.org.uk](http://www.dementiacare.org.uk)

#### **Using personal health budgets**

See [www.nhs.uk](http://www.nhs.uk)

#### **Using personal care budgets**

See [www.ageuk.org.uk/home-and-care/help-at-home/self-directed-support](http://www.ageuk.org.uk/home-and-care/help-at-home/self-directed-support)

#### **Admiral Nursing Direct helpline**

See [www.dementiauk.org/information-support/admiral-nursing-direct/](http://www.dementiauk.org/information-support/admiral-nursing-direct/)

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# 8

## When the carer's own circumstances change

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“ I was frightened of what I was getting into, and as long as I didn't seek help and get 'into the system' as it were, I could go on kidding myself that this wasn't happening and things might not deteriorate.”

### Regular carers' assessments and reviews

Carers of people with dementia will often be in the role for a number of years, and are likely to be elderly themselves, and therefore may have their own health issues. Younger carers may well be managing work, other family commitments and caring, therefore it is highly likely that their own circumstance will change at some point.

A carer's wellbeing can be affected by many different factors including their own health and this can have a significant impact on their ability or willingness to continue in their caring role. Carers may also experience a change in their family, employment or financial situation.

All carers have their own needs, commitments and responsibilities therefore their circumstance could change at any time. A good quality carer's assessment and review structure is vital to highlight any changes or foreseeable changes in the carer's circumstances and give consideration to any support and advice that will help.

### Supporting carers to maintain their own health

It is well documented that carers of people with dementia have poor health outcomes. The more demanding the caring role, the less likely carers are to look after themselves or seek help for their own health. Carers typically report they experience high levels of stress, and struggle with their mental and physical health. Carers of people with dementia can also face the added pressure from stigma associated with the condition, and face particular difficulties in accessing practical and emotional support (Hirst, M, 2005).

Carers will have contact with health and care professionals in the context of their caring role, giving professionals an opportunity to ask them about their own health. It's an opportunity to check they are managing to attend appointments they may have, as well as exploring opportunities and encouraging them to take a break. In some areas, free respite services are available for carers to attend medical appointments, including short hospital stays. Local social care and carers service should be able to advise whether there is such a scheme in the area.

## Work life balance

Maintaining employment can be very important to carers, allowing them to keep their sense of self, have a break from caring and ensure financial security. Carers have the right to request flexible working and time off under the Work & Families Act 2006 and are protected against discrimination at work under the Equality Act 2010. Carers and their employers are not always aware of these rights, resulting in carers giving up work before other options are explored.

A timely referral for a community care assessment for the person with dementia and a carer's assessment will allow an opportunity to explore different care options that may be available, such as personal budgets, allowing the carer to stay in employment.

Carers who work part time may be entitled to Carer's Allowance and other benefits depending upon their financial, family and housing situation. Local advice centres will be able to do a benefits check, to ensure the person with dementia and their carer are receiving everything they are entitled to.

## Further information

### **Carers' assessments**

See [www.carers.org/carers-assessment](http://www.carers.org/carers-assessment)

### **Thinking about carers' health and wellbeing**

See [www.carers.org/help-directory/taking-care-yourself](http://www.carers.org/help-directory/taking-care-yourself)

### **Carers' employment rights**

See [www.carersuk.org/help-and-advice/work-and-career](http://www.carersuk.org/help-and-advice/work-and-career)

### **How the Care Act affects carers**

See [www.gov.uk/government](http://www.gov.uk/government)

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# 9

## When the person with dementia becomes incontinent

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“Incontinence was a problem, I feel I didn’t have any help with it even though we had a Continence Nurse. They used to provide pants, but they just stopped ... It was all the issues around the incontinence that were the final straw ... it would be all over the carpet and he had walked in it, and I thought ‘I just can’t cope with this’.”

### Professionals and carers planning for continence issues

Having early discussions with carers about possible continence issues enables them to plan and access appropriate help and support earlier. Carers may not seek help regarding continence problems because of embarrassment. Therefore, it is better if the subject can be raised by GPs and other health professionals. The carer may well be struggling when a medical condition that could be treated or managed may be the cause of the incontinence.

Carers interviewed for A Road Less Rocky cited incontinence along with difficult behaviour as a primary reason for looking into residential care. Receiving good timely advice on how to manage incontinence is vital and may help towards preventing a break down in the caring role. A referral to the local continence service will ensure carers are given the right advice on management and products available.

### Adequate and appropriate incontinence supplies

Carers will feel more confident about caring for someone with continence problems if they and the person they care for have access to and advice on appropriate products and whether they are available on prescription. This will prevent carers purchasing unnecessary or incorrect items.

## Information and advice about dealing with incontinence

Carers can struggle with the management of incontinence and it can be a pivotal point in the caring journey. Timely substantial advice and professional support can help carers to manage more effectively. Caring for someone with dementia and incontinence has extra pressures as due to their cognitive impairment, people with dementia may not be able to manage or may resist using incontinence aids. There are simple measures and strategies carers can put in place which could help.

## Practical help with laundry

Caring for someone who is incontinent is expensive and time consuming. Even when they are receiving free supplies of incontinence products carers may find themselves topping up. The household laundry will increase, adding to the carer's workload. Practical help in the home and outside laundry services can help and it is always good practice to check the carer has a working washing machine and dryer. There are a number of local and UK wide charitable organisations, including furniture projects that can help with funding towards washing machines and dryers.

### Further information

#### **Help with managing toilet problems**

See [www.alzheimers.org.uk](http://www.alzheimers.org.uk)

#### **NHS advice on incontinence products**

See [www.nhs.uk](http://www.nhs.uk)

#### **Providing care and support with incontinence dementia care**

See [www.alzheimers.org.uk](http://www.alzheimers.org.uk)

#### **Help with funding**

See [www.turn2us.org.uk](http://www.turn2us.org.uk)

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# 10

## When decisions about residential care and end of life care have to be made

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“ My husband was considered to be ‘bed blocking’ ... the social worker told me about four different options that might be suitable for my husband but each one I looked at seemed even more unsuitable than the last, this information should be linked in to when the person gets a diagnosis ... considerations of moving, financial aspects, possibilities of staying together, problems of living apart ... all has to go into the melting pot and a solution gradually reached. ”

### Advice and support about continuing to care at home

There are a number of factors which may precipitate a need for the carer to consider residential care, these are particularly when the person with dementia is no longer safe at home, develops difficult behavioural problems or becomes incontinent. Carers value support and information from professionals when having to make a decision about residential care, as there may be conflicting views from the person with dementia, the carer and possibly the wider family. In order to save time and disappointment, information on which local residential care options offer the correct support for the person with dementia is vital. Carers will often have mixed emotions and benefit from emotional support during this period of change.

### Clear information on all care options

Information at an early stage on the availability and costs of different care options may help relieve some of the stress and panic when the carer is no longer able, or is unwilling to care. Sometimes carers will find themselves having to research care options in a hurry following an accident at home, a hospital stay or the failure of their own health. Carers can feel under pressure to find a place quickly when the person with dementia is ready to be discharged from hospital.

For carers of people with rare types of dementia and/or young onset dementia, finding an appropriate residential home can be particularly difficult. It is quite possible that there will be no local provision, therefore it is important that UK wide as well as local information is made available at an early stage to enable more effective planning for the future.

It is also important to note that when the person with dementia goes into residential care that this is not the end of the caring role. Carers often visit regularly and give social, emotional and practical support.

## Active involvement of carers in decisions about end of life care

Carers can make a valuable contribution in discussions about end of life care and can take an active role in the planning and delivery of the care needed. They know the person with dementia well, so will have insight into their wishes. There may be an advance statement and lasting power of attorney in place giving instructions on end of life care. Professionals can support carers to recognise difficult emotions they feel during this period and refer for appropriate support.

Ideally, information about lasting power of attorney and planning for end of life care should be given early on, following diagnosis, while the person with dementia still has capacity. Making decisions on someone else's behalf can be very difficult and stressful, so planning ahead is vital.

Following bereavement, carers may experience different emotions including loss, relief and guilt. Caring will have been a large part of their life and a feeling of loss of purpose is not uncommon. Good support during this time can help the carer consider their options for the future and prevent a deterioration in their own health.

Planning ahead and having the opportunity to discuss the possibilities of life after caring could help ease the trauma carers may feel at this pivotal time. Encouraging carers to take time out while they are caring and to maintain their social activities will help prevent further isolation when their caring responsibilities end.

## Further information

### **Things to think about when considering residential care**

See [www.ageuk.org.uk](http://www.ageuk.org.uk)

### **Paying for residential care**

See [www.ageuk.org.uk/home-and-care/care-homes/care-homes—6-things-to-think-about](http://www.ageuk.org.uk/home-and-care/care-homes/care-homes—6-things-to-think-about)

### **NHS continuing healthcare funding**

See [www.alzheimers.org.uk](http://www.alzheimers.org.uk)

### **Planning for end of life care**

See [www.dyingmatters.org](http://www.dyingmatters.org)

### **Keeping well when the caring role changes**

See [www.ageuk.org.uk/home-and-care/advice-for-carers/when-your-caring-role-changes](http://www.ageuk.org.uk/home-and-care/advice-for-carers/when-your-caring-role-changes)

### **Grief, loss and bereavement**

See [www.alzheimers.org.uk](http://www.alzheimers.org.uk)

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# Useful contacts

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## Carers Trust

Carers Trust is a major new charity for, with and about carers. We work to improve support, services and recognition for anyone living with the challenges of caring, **unpaid**, for a family member or friend who is ill, frail, disabled or has mental health or addiction problems.

We do this with Network Partners – a unique network of independent carers centres, Crossroads Care schemes and young carers services. Together we are united by a shared vision for carers – to make sure that quality assured information, advice and practical support are available to all carers across the UK.

To find your nearest Network Partner, call 0844 800 4361 or visit [Carers.org](http://Carers.org).

Carers Trust also supports carers through interactive services on [Carers.org](http://Carers.org), [babble.carers.org](http://babble.carers.org) and [matter.carers.org](http://matter.carers.org).

[Carers.org](http://Carers.org)

<https://professionals.carers.org/>

Tel: 0844 800 4361

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

## Admiral Nurses

Admiral Nursing DIRECT is a helpline and email service, provided by experienced Admiral Nurses and is for family and professional carers, people with dementia and those worried about their memory. It gives practical advice and emotional support to anyone affected by dementia.

[www.dementiauk.org/information-support/admiral-nursing-direct/](http://www.dementiauk.org/information-support/admiral-nursing-direct/)

Tel: 0845 257 9406

Email: [direct@dementiauk.org](mailto:direct@dementiauk.org)

## Age UK

Age UK is the country's largest charity dedicated to helping everyone make the most of later life.

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

Tel: 0800 169 6565

Email: [contact@ageuk.org.uk](mailto:contact@ageuk.org.uk)

### **Alzheimer's Society**

Alzheimer's society is a support and research charity for people with dementia and their carers. It provides information and support on all forms of dementia.

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

Tel: 0300 222 11 22

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

### **Compassion in Dying**

Compassion in Dying helps people plan ahead to ensure their wishes will be respected. It works to inform and empower people to exercise their rights and choices around end-of-life care.

[www.compassionindying.org.uk/making-decisions-and-planning-your-care/planning-ahead/](http://www.compassionindying.org.uk/making-decisions-and-planning-your-care/planning-ahead/)

Tel: 0800 999 2434

Email: [info@compassionindying.org.uk](mailto:info@compassionindying.org.uk)

### **Dementia Care**

Dementia care offers support to people with dementia and their carers. It's website is packed with information, including an interactive dementia friendly house.

[www.dementiacare.org.uk/living-well-with-dementia/i-am-a-carer-or-friend](http://www.dementiacare.org.uk/living-well-with-dementia/i-am-a-carer-or-friend)

Tel: 0191 217 1323

Email: [info@dementiacare.org.uk](mailto:info@dementiacare.org.uk)

### **Dementia Handbook**

The Dementia Handbook for Carers aims to answer all the questions family members or friends may have about dementia and its symptoms.

[www.berkshirehealthcare.nhs.uk](http://www.berkshirehealthcare.nhs.uk)

Tel: 0118 9605027.

Email: [bht@berkshire.nhs.uk](mailto:bht@berkshire.nhs.uk)

### **Disability and carers benefits**

A website to find government services and information.

[www.gov.uk/browse/benefits/disability](http://www.gov.uk/browse/benefits/disability)

Tel: 0345 608 4321

### **DLF**

DLF is a UK wide charity providing impartial advice, information and training on independent living.

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

Tel: 0300 999 0004

Email: [info@dlf.org.uk](mailto:info@dlf.org.uk)

### **Dying Matters**

Dying Matters is a coalition of members which aims to help people talk more openly about dying, death and bereavement, and to make plans for the end of life.

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

Tel: 08000 21 44 66

## **MIND**

A mental health charity providing advice and support to empower anyone experiencing a mental health problem. It also campaigns to improve services, raise awareness and promote understanding.

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

Tel: 020 8519 2122

Email: [contact@mind.org.uk](mailto:contact@mind.org.uk)

## **NHS Choices – information on pharmacy services**

NHS Choices offers a wide range of resources that can support health and care professionals in their work with patients and clients.

[www.nhs.uk](http://www.nhs.uk)

Tel: 111

## **Revitalise**

Revitalise is a UK wide charity providing short breaks and holidays (respite care) for disabled people and carers.

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

Tel: 0303 303 0145

Email: [info@revitalise.org.uk](mailto:info@revitalise.org.uk)

## **Royal College of Psychiatrists**

Readable, user-friendly and evidence-based information on various mental health problems, treatments and other topics, regularly updated by psychiatric experts.

<http://www.rcpsych.ac.uk/expertadvice.aspx>

Tel: 020 7235 2351

Email: [reception@rcpsych.ac.uk](mailto:reception@rcpsych.ac.uk)

## **Turn2us**

Turn2us is a UK wide charity that helps people in financial hardship to gain access to welfare benefits, charitable grants and support services.

[www.turn2us.org.uk](http://www.turn2us.org.uk)

## **Young Onset Dementia**

Provides specialist support services for younger people with dementia and their families in Oxfordshire and adjoining areas. For people outside their region they offer signposting and telephone support.

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

Tel: 01993 776295

Email: [mail@youngdementiauk.org](mailto:mail@youngdementiauk.org)

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Hirst, M (2005), 'Carer distress: a prospective, populations-based study', *Social Sciences & Medicine*, 61, 3, Aug, 697–798.

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[matter.carers.org](http://matter.carers.org)  
[babble.carers.org](http://babble.carers.org)  
<http://professionals.carers.org>

[www.facebook.com/CarersTrust](http://www.facebook.com/CarersTrust)  
[www.twitter.com/CarersTrust](http://www.twitter.com/CarersTrust)  
[www.youtube.com/user/CarersTrust](http://www.youtube.com/user/CarersTrust)

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