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**Next steps after diagnosing dementia: interventions to help patients and families.**

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## **ABSTRACT**

The way that a diagnosis of dementia is delivered to patients, what information is provided and what practical advice and support is arranged will have a lasting impact and deserves at least as much attention as the process of assessment and investigation. An honest yet sensitive discussion about the nature and cause of the problems is needed, using non-technical language and tailored to the priorities and needs of the individual and their family. This should lead on to provision of good quality information in an accessible format. Interventions to prioritise will include medication review, attention to sensory deficits, appropriate pharmacological and nonpharmacological treatment, best use of memory aids and strategies, and driving, financial entitlement and legal advice. Referral onwards should be made to an appropriate individual or service who will be able to provide ongoing emotional and practical support and signposting.

## **INTRODUCTION**

Receiving a timely diagnosis of dementia and its subtype can have many benefits, but it also presents many challenges.<sup>1</sup> Confirmation that changes in cognitive ability and day to day functioning have a medical cause and giving a name to it is often a relief, providing an explanation for the difficulties being experienced and reducing anxiety of both the person with dementia and their families and carers.<sup>2,3</sup> However, a positive outcome will depend on the communication skills of the clinician to deliver a good understanding of the diagnosis and its implications. They should also take responsibility for arranging what happens next.

Unfortunately, disclosure of dementia diagnosis is sometimes poorly handled and post-diagnostic support is too often inadequate.<sup>4</sup> Some clinicians are reluctant to provide a precise diagnosis or to explain prognosis and some avoid using the 'D' or 'A' word, clouding the truth by using euphemisms such as age-related changes or problems with the blood supply, or hiding behind technical terminology such as hippocampal atrophy or neurocognitive disorder. Too often the time spent in explanation is inadequate and people still report that information was given in an abrupt or insensitive manner. By contrast, a clear and sensitive discussion about diagnosis, tailored to the stage of the condition and the priorities and needs of the person with dementia and those caring for them, should lead on to considering practical interventions allowing all involved to 'live well with dementia'.<sup>5,6</sup>

## **TELLING THE DIAGNOSIS**

All people with dementia have the right to know their diagnosis and most will wish to be fully informed.<sup>7</sup> Disclosing diagnosis to the family only or allowing them to refuse the person with dementia being told is rarely justifiable. Rather, the person with dementia must be given the opportunity to learn as much or as little as they want to know. It is not for professionals (or family, or carers) to decide, but to respond by providing information with empathy and understanding. Those affected by anosognosia who may be unaware of their cognitive deficits need to be handled with particular care in order to avoid an argumentative or angry reaction.

With patient consent, telling the diagnosis should ordinarily occur in a joint meeting with family. As with any difficult consultation it will go best when structured, for example using the SPIKES six step protocol for delivering bad news (Table 1).<sup>8</sup>

**Table 1. Six-step SPIKES model for delivering bad news <sup>8</sup>**

**S - SETTING UP**

- Review the plan for giving the diagnosis
- Ensure environment appropriate and no distractions
- Involve significant others
- Establish rapport
- Manage time constraints and ensure no interruptions

**P - PERCEPTION**

- Explore people's knowledge, what they suspect, and hopes
- Consider level of understanding and retention
- Establish any lack of insight, denial or unrealistic expectations

**I – INVITATION or INFORMATION**

- Establish what information is wanted
- Accept people's right not to know
- Offer to answer any questions later if wanted
- Ask if happy to share information with relatives or friends

**K – KNOWLEDGE**

- Give warning shot that bad news is coming
- Match explanation to level of comprehension
- Use non-technical language
- Deliver information in small chunks
- Periodically check understanding of what has been said
- Get to the point but avoid unnecessary bluntness
- Don't be relentlessly negative - highlight strengths as well as weaknesses

**E – EMPATHY**

- Anticipate and recognise people's fears and concerns
- Identify the reason for the emotion
- Be supportive by combining empathic, exploratory and validating responses
- Be mindful of your own emotional response

**S – STRATEGISE and SUMMARISE**

- Ask if people want anything clarified
- Acknowledge and answer questions
- Understand important specific goals that people may have
- Explain available support and negotiate management plan
- Summarise and agree follow up
- Be realistic but try to end by highlighting the positives

Sufficient time must be available to explain complexities in a manner accessible to both the person with dementia and those accompanying them.<sup>9</sup> The presence of cognitive impairment means there will be a greater need than usual to repeat information and to check its understanding, rephrasing as necessary. It is helpful to write down the important points so that they can be re-read as often as required and be taken away after the consultation.

It is important to use both the term dementia and its subtype explicitly due to differences in disease course and management. Given the growing public awareness of Alzheimer's disease, this diagnosis may not come as a surprise but misconceptions and misunderstandings about terminology will still need to be cleared up, most commonly the difference between dementia and Alzheimer's disease. Use of the term *probable* Alzheimer's disease is best avoided as it raises the spectre of diagnostic uncertainty and may frustrate and confuse people. Less common conditions such as Lewy body and frontotemporal dementias will need fuller explanation and terms such as primary progressive aphasia and posterior cortical atrophy are best described as particular presentations of subtypes of dementia, rather than specific medical conditions. Given that the consequences of stroke are widely perceived in terms of physical function, it may be necessary to emphasise that a vascular dementia is a consequence of a past stroke rather than a new medical condition. Similarly, unless clarified, many people's previous understanding of Parkinson's disease as solely a movement disorder may suggest to them that dementia is a second diagnosis, or raise concern about previous misdiagnosis.

Accurately predicting the rate of decline of dementia is challenging. Nevertheless, telling a diagnosis without a prognosis has limited value and effort should be made to honestly describe the likely impact on independence and survival. Specific numbers are best avoided, but explaining that dementia overall increases risk of mortality about two-fold can be helpful (with frontotemporal dementia having nearly double the risk compared to Alzheimer's disease, with other subtypes in between).<sup>10</sup>

## **PROVIDING INFORMATION**

The first priority after diagnosis disclosure is provision of relevant information, both verbal and written (Figure 1). Planning another face-to-face meeting soon after initial disclosure is good practice providing opportunity to repeat information not taken on board initially, to clear up misconceptions and to expand on important issues. Care needs to be taken to ensure the person with dementia is always at the centre of discussions, as carers can easily become dominant. With patient

consent, separate meetings with the family may be helpful to speak more easily about their particular concerns such as genetic risk, practising a non-confrontational approach to managing difficult behaviours and planning future living arrangements and prognosis.

Directing people to quality information in print or on trustworthy websites will be helpful. The Alzheimer's Society publish a 'Dementia Guide',<sup>11</sup> available in multiple formats and languages. They also have more detailed factsheets on relevant topics and introductory booklets addressing younger onset dementia and each of the less common dementia subtypes. These overcome the problem that much of what is available is generic and 'alzheimerised'. The Reading Well Books on Prescription scheme has 37 recommended books on dementia that are all available to borrow free from local libraries. These include not only books giving factual information and advice, but also accounts of real life experience of living with dementia that some people will find more illuminating.

For those used to getting their information online, the Dementia Information Service run by NHS England provides a weekly email to guide people through the first six weeks after diagnosis. Providing addresses of reliable websites will be helpful, together with a general warning about shortcomings of health information online. Dementia Talking Point is the Alzheimer's Society's online community, allowing anyone affected by dementia to join in discussions and to support each other. Setting up a private group with other family members and friends can help with engagement and ensure everyone is kept in the loop.

Social media encourages peer-based information exchange rather than the traditional expert-led model, so providing a more empowered and patient-centred experience.<sup>12</sup> Social networking sites such as Facebook host local and national dementia support groups and such online forums may be especially useful for those with less common dementia subtypes who are always in the minority in other settings. Twitter is dominated by links to third party sites, rather than personal anecdotes or experiences.<sup>13</sup> Instagram may be helpful for people who are best with visual information. Of YouTube videos about Alzheimer's disease, testimonial videos have the highest views suggesting that this is preferred rather than a more didactic approach.<sup>14</sup>

Some general principles of information giving to a newly diagnosed person with dementia and their carer are listed in Table 2 and good sources of information in the UK are listed in Table 3.

**Table 2. NICE guidance<sup>15</sup> on information provision to people living with dementia and their family members or carers at time of diagnosis. All information should be relevant to their circumstances and the stage of their condition.**

Provide oral and written information that explains:

- what their dementia subtype is and the changes to expect as the condition progresses
- which health professionals and social care teams will be involved in their care and how to contact them
- if appropriate, how dementia affects driving, and that they need to tell the DVLA and their car insurer about their dementia diagnosis
- their legal rights and responsibilities
- their right to reasonable adjustments (in line with the [Equality Act 2010](#)) if they are working or looking for work
- how local support groups, online forums and national charities, financial and legal advice services and advocacy services can help and how to contact them.
- If it has not been documented earlier, ask the person for their consent for services to share information, which people they would like services to share information with (for example family members or carers) and what information they would like services to share. Document these decisions in the person's records.
- Direct people and their family members or carers (as appropriate) to relevant services for information and support
- For people who do not want follow-up appointments and who are not using other services, ask if they would like to be contacted again at a specified future date.
- Ensure that people living with dementia and their carers know how to get more information and who from if their needs change.
- Tell people living with dementia (at all stages of the condition) about research studies they could participate in.



**Table 3. Useful sources of information and support for people newly diagnosed with dementia and their carers**

**National telephone helplines (practical advice and emotional support)**

Alzheimer's Society (England and Northern Ireland)	0300 222 1122
Alzheimer Scotland	0808 808 3000
NHS Direct in Wales	0808 808 2235
Dementia UK (Admiral Nurses)	0800 888 6678

**Support Organisations**

Alzheimer's Society (England, Wales & Northern Ireland)	<a href="http://www.alzheimers.org.uk">www.alzheimers.org.uk</a>
Alzheimer's Scotland	<a href="http://www.alzscot.org">www.alzscot.org</a>
Rare Dementia Support	<a href="http://www.raredementiasupport.org">www.raredementiasupport.org</a>
The Lewy Body Society	<a href="http://www.lewybody.org">www.lewybody.org</a>
Carers Trust	<a href="http://www.carers.org">www.carers.org</a>
Carers UK	<a href="http://www.carersuk.org">www.carersuk.org</a>
Stroke Association	<a href="http://www.stroke.org.uk">www.stroke.org.uk</a>
Parkinson's UK	<a href="http://www.parkinsons.org.uk">www.parkinsons.org.uk</a>
Young Dementia UK	<a href="http://www.youngdementiauk.org">www.youngdementiauk.org</a>

**Books**

Books on prescription (including first hand accounts)	<a href="http://www.reading-wel.org.uk/books/books-on-prescription/dementia">www.reading-wel.org.uk/books/books-on-prescription/dementia</a>
<ul style="list-style-type: none"><li>• A Pocket Guide to Understanding Alzheimer's Disease and Other Dementias (2nd edition), by James Warner and Nori Graham. Jessica Kingsley Publishers, 2018.</li><li>• Dementia: The One-Stop Guide: Practical advice for families, professionals, and people living with dementia and Alzheimer's disease, by June Andrews. Profile Books Ltd, 2015.</li></ul>	

**Online dementia education courses**

Dementia Information Service (NHS England)	<a href="http://www.nhs.uk/conditions/dementia/dementia-information-service">www.nhs.uk/conditions/dementia/dementia-information-service</a>
Staying connected and living well	<a href="http://www.futurelearn.com/courses/dementia-care">www.futurelearn.com/courses/dementia-care</a>
Living well as dementia progresses	<a href="http://www.futurelearn.com/courses/comfort-care">www.futurelearn.com/courses/comfort-care</a>

## **Driving**

DVLA

Driving mobility (driving courses and assessments)

Blue Badge

[www.gov.uk/dementia-and-driving](http://www.gov.uk/dementia-and-driving)

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

[www.gov.uk/government/publications/blue-badge-can-i-get-one](http://www.gov.uk/government/publications/blue-badge-can-i-get-one)

## **Benefits and finances**

Department of Work and Pensions

DirectGov (Benefits and claim forms)

Lasting Power of Attorney

Money Advice Service

Citizens Advice

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

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

[www.lastingpowerofattorney.service.gov.uk](http://www.lastingpowerofattorney.service.gov.uk)

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

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

## **Research**

Join Dementia Research

Alzheimer's Research UK

[www.joindementiaresearch.nihr.ac.uk](http://www.joindementiaresearch.nihr.ac.uk)

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

## **Adaptations, equipment and technology**

Equipment for independent living

Telecare Services

Assistive technology

<https://asksara.dlf.org.uk>

[www.tsa-voice.org.uk/support-at-home](http://www.tsa-voice.org.uk/support-at-home)

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

## **Therapeutic activities**

Accessible touchscreen apps for entertainment

BBC Reminiscence Archive

Dementia-friendly arts events and opportunities

Singing for the Brain

Person-centred activity products

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

<https://remarc.bbcrewind.co.uk/index.html>

[www.arts4dementia.org.uk](http://www.arts4dementia.org.uk)

[www.alzheimers.org.uk/get-support/your-support-services/singing-for-the-brain](http://www.alzheimers.org.uk/get-support/your-support-services/singing-for-the-brain)

[www.active-minds.org/uk/](http://www.active-minds.org/uk/)

## SOURCES OF FUTURE SUPPORT

The details of a single named contact should be provided at an early stage who will be able to answer questions and provide ongoing advice, support and signposting to local services. These people are variously termed as dementia navigators, advisers, link workers, key workers or support workers. They are most effective when they have a long-term involvement, with regular face to face contact. A key role of the care coordinator is to develop a personalised care and support plan. Ideally, they should come from a health/clinical background and work as part of a multidisciplinary team.<sup>16</sup> In Scotland, the government has guaranteed at least a year's post-diagnostic support from a named individual for everyone diagnosed with dementia.

Major sources of practical guidance and support are third sector organisations, though availability of services differs greatly from area to area. In the UK, the Alzheimer's Society (and Alzheimer Scotland) provide post-diagnostic information and support services for all types of dementia and have a comprehensive online directory of regional and local services and activities. These include Alzheimer Cafés, Singing for the Brain, Games for the Brain, education programmes, befriending and advocacy services, carer support groups and social and activity groups. Their Dementia Connect Programme aims to use expert Dementia Advisors to identify individual needs and to help put in place personalised support plans to address them. The information and support needs of subtypes of dementia are the focus of Rare Dementia Support at the UCL Dementia Research Centre, the Lewy Body Society, Parkinson's UK and the Stroke Association. Younger people with dementia prefer to receive support from bespoke services rather than generic provision and specific post-diagnostic teams for those of working age are available in some areas. Young Dementia UK and the associated Young Dementia Network can provide age-appropriate information and has a prominent role nationally in advocating for and supporting younger people with dementia.

Dementia UK offers help to families living with dementia through contact (by telephone helpline and face-to-face) with the Admiral Nurse Service. These specialist dementia nurses help families to understand dementia better and to develop the skills needed to effectively manage the condition and offer psychological support to family carers.<sup>17</sup> Addressing the needs of carers are also the centre of attention of Carers UK and the Carers Trust. NICE recommends that carers should be advised about their right to a formal assessment of their own needs (known as a 'Carer's Assessment'), as well as need for short breaks and other respite care.<sup>15</sup> They also should be offered specific psychoeducation and communication and behavioural management skills training. This should be in a format suitable

for them, on an individual basis such as the 8 week manual based START programme,<sup>18</sup> or in group sessions with other carers, or online. Peer-support groups and networks are also highly valued by people with dementia and their carers, particularly by those with rarer subtypes, or onset at a younger age.

## **MEDICATION**

Families often think that drugs are available to ‘treat’ dementia and are eager for an immediate prescription. It is wiser to first instigate a thorough medication review, stopping all inappropriate and potentially unnecessary drugs, especially those with anticholinergic effects and central nervous system depressants such as benzodiazepines and opiates. Whenever possible, dosage regimens should be simplified so that all medication can be taken together once daily. This may reduce errors more effectively than medication compliance aids such as Dossett boxes and blister packs that are widely used, despite little evidence that they improve compliance or safety. They also risk engendering a false sense of security amongst carers and prescribers that medication will be taken reliably (Figure 2).<sup>19 20</sup>

The subtype and severity of dementia will decide whether antidementia drug treatment may be suitable. Of the available drugs, NICE guidance<sup>15</sup> recommends offering a cholinesterase inhibitor (donepezil, rivastigmine or galantamine) as monotherapy in mild or moderate Alzheimer's disease, dementia with Lewy bodies or Parkinson's disease dementia. Memantine should be considered for people with moderate Alzheimer's disease or dementia with Lewy bodies and Parkinson's disease dementia if cholinesterase inhibitors are not tolerated or are contraindicated, or if someone presents with severe dementia. Memantine also can be added later to established treatment with a cholinesterase inhibitor if dementia has progressed to a moderate or severe stage. The drugs should only be considered for people with vascular dementia if they have suspected comorbid Alzheimer's disease, Parkinson's disease dementia, or dementia with Lewy bodies (mixed dementia).

Checking the pulse rate before initiating cholinesterase inhibitor treatment is appropriate in all patients, but a routine ECG is unnecessary unless there is bradycardia or history of unexplained syncope.<sup>21</sup> Known cardiac contraindications do need to be considered and caution is appropriate when people are taking cardiac rate-limiting drugs, such as beta-blockers, non-dihydropyridine

calcium channel blockers, digoxin or amiodarone, when reducing the dose or switching to an alternative drug may be an option.

All the cholinesterase inhibitor drugs have similar efficacy, but donepezil is usually first choice and has the advantage of simple dosage regimen. NICE recommends that as long as the recommendation to start has been made by a clinician with the necessary knowledge and skills, the first prescription may be made in primary care. Everyone needs to understand that benefits are likely to be modest and they do not alter the course of the condition, so should not be stopped just because there is no improvement or when later dementia severity increases. Details the indications, cautions and contraindications for the available antidementia drugs are listed in Table 4.

**Table 4. Indications, cautions and contraindications to available antidementia medication.**

<b>Drug (dose)</b>	<b>Indications</b>	<b>Cautions</b>	<b>Contraindications</b>
<p><b>Acetylcholinesterase inhibitors (AChEi):</b> start at low dose and increase according to response and tolerability</p> <p><b>Donepezil</b> (5-10mg od by mouth)</p> <p><b>Galantamine</b> (8-24mg modified release od by mouth)</p> <p><b>Rivastigmine</b> (1.5-6mg bd by mouth, or 4.6-13.3mg/24h transdermal patch)</p>	<ul style="list-style-type: none"> <li>• Mild-moderate Alzheimer’s disease</li> <li>• Dementia with Lewy bodies</li> <li>• Parkinson’s disease dementia</li> </ul>	<ul style="list-style-type: none"> <li>• Pulse 50-60bpm (consider ECG)</li> <li>• Cardiac rate-limiting drugs</li> <li>• COPD or history of asthma</li> <li>• Significant GI symptoms</li> <li>• Susceptibility to peptic ulcer</li> <li>• History of seizures</li> <li>• Bladder outflow obstruction</li> <li>• Hepatic impairment</li> </ul>	<ul style="list-style-type: none"> <li>• Pulse &lt;50bpm</li> <li>• Heart block</li> <li>• Sick sinus syndrome</li> <li>• QT prolongation</li> <li>• Significant airways obstruction</li> <li>• Active peptic ulcer</li> <li>• Known hypersensitivity</li> </ul>
<p><b>NMDA antagonist</b></p> <p><b>Memantine</b> (5-20mg od by mouth – titrate up in 5mg steps each week)</p>	<ul style="list-style-type: none"> <li>• Severe Alzheimer’s disease</li> <li>• Moderate Alzheimer’s disease, dementia with Lewy bodies, or Parkinson’s disease dementia if people cannot tolerate, or have a contraindication to AChEi</li> </ul>	<ul style="list-style-type: none"> <li>• Renal impairment (may need reduced dose)</li> <li>• Severe hepatic impairment</li> <li>• Concurrent use of other NMDA antagonist (amantadine, ketamine, dextromethorphan)</li> </ul>	<ul style="list-style-type: none"> <li>• History of seizures</li> <li>• Known hypersensitivity</li> </ul>

People with a vascular or mixed dementia may benefit from aggressive vascular risk factor management as recommended for secondary stroke prevention,<sup>22</sup> though it should be explained that this can only reduce risk of further damage rather than ameliorate established dementia. In frontotemporal dementia, selective serotonin reuptake inhibitors at high dose may help behavioural and psychological symptoms - especially disinhibition, irritability and depression - though they have no positive effect on cognition.<sup>23</sup>

No disease modifying treatments have yet been shown to be effective in established dementia, but many drugs are in clinical development.<sup>24</sup> Whilst interest in experimental treatments for dementia is often stimulated by exaggerated media reports, all patients should be encouraged to explore opportunities to take part in clinical research. By registering their interest with Join Dementia Research,<sup>25</sup> people across the UK can be matched with studies open to recruitment, not just of pharmacological treatments but also of psychosocial interventions and observational studies.

## **PRACTICAL INTERVENTIONS IN DAILY LIFE**

Discussion about interventions to help manage current and future challenges in day to day life is usually welcomed and timely referral to appropriate services, such as occupational therapy or social services, will help to keep people living well and should promote autonomy. However, this needs to be conducted sensitively, bearing in mind that the person with dementia may not be fully aware of the extent of their functional deficits or their implications and family carers may need time to adjust to the impact on their own lifestyle and future plans. Ill-timed advice on changes to personal routine and advance care planning, or premature referral to other professionals and agencies may merely engender resentment, increase patient and carer anxiety, and result in unnecessary dependency. Planning ahead is sensible, but for many people with a new dementia diagnosis there is often little immediate need or benefit of rushing to make major changes to activities and routines that were in place before. It is important to allow time for people to come to terms with the diagnosis and its implications and for them not to feel they must tackle everything at once.

Younger people with dementia may still be working at the time of diagnosis and many can continue to do so depending on the type of work. Advice about talking to their employer at an early stage is appropriate. Sometimes this is a contractual requirement, but it is also necessary if driving is involved and it is sensible if there are safety issues or legal or financial responsibilities that need to be considered. Seeking advice from a Disability Employment Adviser or involving occupational

health or trade union representatives may be helpful. Rather than giving up work, flexible working hours or a change of role may be possible, bearing in mind that dementia is classified as a disability and therefore employers must make 'reasonable adjustments' to accommodate any difficulties. Family carers also have the legal right to request flexible working hours to support the person with dementia.

People will be keen to keep the brain active. However, whilst crosswords or puzzles such as Sudoku may be enjoyable for those used to doing them, it is better to suggest more socially-oriented activities if people are wanting to take up something new. Encouraging use of familiar memory aids such as making lists, calendars, digital clocks, wipe clean noticeboards and strategically placed sticky notes is often helpful (Figure 3). Electronic aids such as smart speakers, locator or prompt devices, dementia-specific apps (for both the person with dementia and carers) and other assistive technology are playing an increasing role in dementia management.<sup>26</sup> There is very limited evidence to support the efficacy of formal cognitive training (guided practice on structured tasks to improve or maintain particular cognitive abilities).<sup>27</sup> Group cognitive stimulation (regularly engaging in a range of themed activities and discussions in a social setting) has the most consistent supportive evidence and should be offered.<sup>28</sup> Group reminiscence (discussion of memories and past experiences using prompts to evoke memories and stimulate conversation)<sup>29</sup> and individual cognitive rehabilitation/reablement (focusing on realistic functional goals tailored to the individual, building on strengths and finding ways to compensate for impairments)<sup>30</sup> can also be considered.

Any significant sensory deficits should have been identified during diagnostic workup. There is need then for good communication with professionals relevant to hearing or vision and prescription of corrective devices or other intervention as appropriate.<sup>31 32</sup> For those with hearing loss, recommending a simple intervention such as ear syringing, or cleaning or servicing hearing aids may be all that is necessary to improve hearing and cognitive performance. If problems remain then referral to the audiology service is indicated. Those with visual problems, whether due to sight loss or perceptual deficits, may benefit from environmental modifications such as strategic use of contrasting colours, non-pattern flooring and automatic lighting. Uncorrected refractive errors will impair cognitive performance and making sure that the person has clean, up-to-date spectacles and uses them consistently is essential. Half of post-refraction visual impairment among people with dementia is due to cataracts and expediting surgery may be appropriate.<sup>33</sup>



The benefits of continuing to keep socially active and maintaining leisure interests and hobbies should always be emphasised. It will be useful to explain that simplifying activities, decluttering, following a routine and minimising distractions are all likely to help performance. It is wise to emphasise the value of planning ahead, allowing more time, doing things one at a time and not taking it for granted that something will work out just because it has never presented difficulty in the past. General advice on maximising physical and cognitive wellbeing by taking regular exercise, not smoking, limiting alcohol, maintaining a healthy diet and managing other comorbidities appropriately should not be overlooked.

Carers should be alerted to the challenges presented by less familiar environments and change in routines and the risk of delirium associated with acute illness or surgery. They should also be made aware of 'John's Campaign' ([www.johnscampaign.org.uk](http://www.johnscampaign.org.uk)) to allow family carers of people with dementia to stay with them when admitted to hospital and of the Alzheimer's Society 'This is me' leaflet ([www.alzheimers.org.uk/get-support/publications-factsheets/this-is-me](http://www.alzheimers.org.uk/get-support/publications-factsheets/this-is-me)) on which people with dementia record details about their likes and dislikes, routines and personal history which can then be shared with healthcare staff if they find themselves in an unfamiliar setting.

## DRIVING

A diagnosis of dementia does not in itself mean that the person is no longer safe to drive. Many people with mild dementia are able to continue to drive for the time being, whilst nearly all those with more severe dementia are not. Fitness to drive is impaired in non-Alzheimer dementias earlier than in Alzheimer's disease, due to behavioural or motor symptoms increasing risk in addition to cognitive factors.<sup>34</sup> Any severity of dementia requires that the Driver and Vehicle Licensing Agency (DVLA) and vehicle insurance company are informed and it is a professional responsibility that clinicians explain this.<sup>35</sup> If the person is obviously unfit to drive, they should be told this unequivocally and helped to surrender their licence immediately, or the clinician should inform the DVLA on their behalf if necessary. In other circumstances, it is best to reflect with the person on the benefits and risks of driving and emphasise the legal requirement rather than express a personal opinion on their safety, especially as clinicians are generally poor at predicting this. This also helps to avoid a difficult conversation deteriorating into an argument that will make it less likely the person will accept advice. The risk of withdrawal of the driving licence or likelihood that it will be

subject to more frequent review and eventual withdrawal in future should be explained. Whilst the person still has a valid licence, a driving assessment at a local centre may help inform the decision.

Losing a driving licence can be a major blow to self-esteem as well as independence and wellbeing. An early discussion of practical alternatives is appropriate (e.g. public transport, taxis, lifts from friends) so that usual activities and interests can continue uninterrupted. Recent changes to Blue Badge parking regulations in the UK to include people with a 'hidden disability' mean that some people with more severe dementia may now qualify, helping carers with parking closer to where they need to go.

## **FINANCES, BENEFITS AND LEGAL ISSUES**

For many people with dementia and their families there will be concern about finances.<sup>36</sup> Younger people with dementia in particular may have to consider early retirement and they are more likely to have dependent children and other commitments such as a mortgage. Advice on benefits and help with applications is available from Citizens Advice offices or local welfare rights officers.

Simplifying money management will help to reduce risks. A third-party mandate will allow help with banking, but is only valid whilst the person retains capacity to manage the account themselves. Direct debits to pay regular bills will ensure they are not overlooked. Paying for things with debit or credit cards may be easier using contactless payment, or a chip and signature card that avoids problems with remembering PIN numbers. Depending on the severity of dementia and its impact on the person's daily living activities, they may be entitled to the attendance allowance (or personal independence payment if under age 65) and may then be disregarded when calculating council tax payments if they have 'severe mental impairment'.

Whilst people still have capacity to do so, they should be encouraged to make a will and a Power of Attorney. This can be done through a solicitor, or online. The Alzheimer's Society also offer a digital assistance service to help complete the forms on the person's behalf. At an early stage it may be appropriate to start discussion about other aspects of advance care planning<sup>37</sup>, such as making an advance statement expressing priorities and preferences for the future and an advance decision to refuse treatment (advance directive in Scotland and Northern Ireland). Specific help with this are available, such as the 'Planning for your future care' guide<sup>38</sup> and the 'Coordinate My Care' service ([www.coordinatemycare.co.uk](http://www.coordinatemycare.co.uk)) currently available across London. If mental capacity has already

been lost by the time of diagnosis, a carer or family member can apply to become a Deputy (or equivalent) that may allow them to make certain decisions on the person's behalf.

## **CONCLUDING REMARKS**

Receiving a dementia diagnosis is life-changing, not just for the person directly affected, but also for their family members and others who will be caring for them. They should not be left with uncertainty about what the diagnosis means, what interventions will be helpful, and how these can be arranged. What they want is:

- Complete information about the condition, presented in non-technical language.
- Recognition that the person with dementia and family members may each have differing values, priorities and concerns, and their own individual circumstances and needs.
- Timely advice, treatment and practical support that will keep the person with dementia as independent as possible throughout the course of the illness.
- Someone to talk to who understands their worries and wants, and can put them in touch with appropriate help at the time it is needed in the future.

Those responsible for assessment and diagnosis must therefore put as much time and effort into what happens next, telling the diagnosis sensitively but clearly, engaging patients and family in all decisions, and ensuring planned follow up meets individual needs.

## **KEY POINTS**

- Most people with dementia want to be told their diagnosis, using non-technical language and avoiding euphemisms.
- The person with dementia should not be excluded from discussions and carers should not dominate the consultation or take over. Both will have needs that should be addressed.
- Verbal information needs to be supplemented by good quality written information, in print or on trustworthy websites.

- Interventions should be individualised, appropriate to the stage and subtype of dementia and tailored to each patient's and carer's needs and priorities.
- Details of a single named contact should be given after diagnosis, to answer questions and provide ongoing advice, support and signposting to local services.

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None

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## FIGURE LEGENDS

Figure 1. Relevant written information should be readily available in clinic areas



Figure 2. Medication compliance aids may highlight non-adherence to drug regimens rather than ensure adherence.



Figure 3. Simple memory aids in everyday life – a digital clock, shopping list on a smartphone, sticky pad message, magnetic timer alarm

