Right care, right place, right time: How can we improve health and care for vulnerable older people?
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1 Alzheimer’s Society

Alzheimer's Society is the UK’s leading support services and research charity for people with dementia and those who care for them. It works across England, Wales and Northern Ireland. The Society provides information and support for people with all forms of dementia and those who care for them through its publications, dementia helplines and local services. It runs quality care services, funds research, advises professionals and campaigns for improved health and social care and greater public awareness and understanding of dementia.

2 Staying healthy for longer: concentrating on prevention and managing long term conditions

2.1 How can we strengthen the incentives, or increase flexibility, for GPs to effectively manage the health of the local population?

Alzheimer’s Society recognises the crucial role of general practitioners in tackling the dementia challenge. There must be appropriate incentives for GPs to continue to drive and increase diagnosis rates of people with dementia in their local area. This must also be supported by effective commissioning beyond the GP practice that ensures once people have a diagnosis, they are able to access quality post-diagnostic support and care.

There are currently 800,000 people with dementia in the UK and this is set to over a million people with dementia by 2021. Dementia will be one of the largest challenges for the health and social care sector into the future. Dementia is often under-diagnosed and diagnosed late. Only 44% of people in England with dementia currently have a diagnosis (Alzheimer’s Society 2013). People also face long waits, with some people waiting up to a year to access a memory assessment.

To manage the health of the local population, GPs must firstly be equipped with comprehensive local data and demographic information. The dementia prevalence calculator, based on the Quality Outcomes Framework, currently provides GPs with their local dementia diagnosis rates and the estimated numbers of people living with dementia in that area. While this is a start, information from the prevalence calculator should be provided in a central spreadsheet in easy to access format rather than the current, often easily confused, map and calculator formats. This must publically available to ensure transparency and accountability to outcomes. Ideally, the Society believes an integrated data set brining together all local data on dementia needs to be developed and made publicly available.
Achieving the Government ambition to increase diagnosis rates to 66% by 2015 will require the full support and effort of all GPs across the country. So far, change in the practice of dementia diagnosis has been successful but must go further. The dementia Direct Enhanced Service has had the highest uptake (59%) of the four proposed as part of the 13/14 GP contract (Pulse Magazine, August 2013). This uptake level indicates that as an incentive this has been successful. Alzheimer’s Society advocates for the continuation of the dementia DES in the 2014/15 GP contract.

As GPs do not operate in isolation, effectively managing the local health population depends on the effectiveness of health and social care commissioning. GPs need to be supported and enable to make an early diagnosis of dementia. To do this, there needs to be a seamless and timely progress between the patient’s initial consultation, referral and formal memory assessment. Memory assessment services are essential and are the NICE recommended point of referral for a diagnosis of dementia. Yet, evidence suggests that there is currently under-provision and variable quality in memory assessment services across the country. CCGs are responsible for commissioning secondary care, which includes the commissioning of memory assessment services. Therefore CCGs also have a key role in supporting GPs by ensuring that memory assessment services area available and accredited in their local area.

Commissioning must also focus on the provision of post diagnostic support for people with dementia. An early diagnosis is the critical first step in being able to better manage an individual’s health and support long term care planning. Commissioners must recognise and fund quality post diagnostic services to ensure that once GPs make a diagnosis, they are then able to offer a range comprehensive care and support packages. Ensuring that this is in place will also breakdown many of the barriers to GPs making a timely diagnosis of dementia and better managing the local health population.

2.2 In your experience, how do you suggest people can be better supported to manage their own care?

To better manage their own care for longer, people with dementia need to have had a timely diagnosis. Despite significant political attention over the last two years, ensuring a timely diagnosis for people with dementia remains a contentious issue. Yet, the evidence shows us that a timely diagnosis supports people with dementia to access treatments earlier on, to plan and make decisions about their care, and importantly to retain their independence and support people to live well with the condition.

People with dementia must have access to quality post diagnostic support, such as The Think Again programme, by Avon and Wiltshire Mental Health Partnership NHS Trust. This programme demonstrates effective post-diagnostic support that goes beyond the simple provision of information. Over eight weeks, therapeutic group sessions explore strategies to cope with changes that living with dementia will bring, for both the person with dementia and their family and/or carer.

People with dementia want to live independently for as long as possible. Good housing and support enhance quality of life for people living with dementia.
Community-based solutions to housing can prevent people from unnecessarily accessing healthcare, and support people to live longer in their own homes. Local authorities need adequate financial resourcing to ensure that they can commission and offer a range of appropriate services to people with dementia. Focusing on preventative and early adjustments, in partnership with health and social care colleagues, could maximise the potential for savings and enhanced wellbeing.

To assist people with dementia to live well with the condition, Alzheimer's Society has been leading, with its partners, in the development of creating dementia-friendly communities. Dementia-friendly communities are places where people with dementia feel confident that they can contribute and participate in activities which are meaningful to them.

Our report, Building dementia-friendly communities: A priority for everyone, found that overwhelmingly, people with dementia want to better health and to get out more locally but feel there are too many things stopping them. To manage their care and improve their quality of life, people with dementia want to live in a community where early diagnosis and personalised and integrated care are the norm, and people with dementia can continue to live independent lives with the support of the health and social care and organisations in their community.

Overall, Alzheimer's Society considers that when you get it right for people with dementia, care and community life will be more inclusive for a much wider range of people, including our most vulnerable. We encourage organisations, communities including all stakeholders in the NHS, to be part of the dementia-friendly communities movement and to sign up to the recognition process at www.alzheimers.org.uk/recognitionprocess.

2.3 Can you share any best practice examples of how to strengthen prevention and early diagnosis in primary and community services?

Alzheimer's Society ran two early diagnosis pilot projects to increase diagnosis rates in Dorset and Warwickshire. Activity included:

- targeting media outlets to highlight the issue of under diagnosis
- engagement with local stakeholders
- dementia awareness events throughout the community
- distribution of Worried about your memory? materials, and
- engagement with local GPs and health providers.

Impressively, both areas saw dramatic improvements in the uptake of information on early diagnosis and the number of people acting on concerns about dementia. There has been an increase in memory clinic referrals and 60% of GP practices in the communities reported an increase in the size of their dementia registers over the period of the pilot project.

This demonstrates that a combined approach, incorporating public awareness raising, media activity, health professional engagement and stakeholder engagement, can improve awareness of dementia.
3 Named clinician: providing a single, named contact to coordinate an individual’s care

3.1 How do you identify vulnerable older people or people most at risk in the local area?

As part of the Quality Outcome Framework under the General Medical Contract, GPs are rewarded for establishing and maintaining a register of patients diagnosed with dementia. This register identifies people with a diagnosis of dementia living in the local area and, pending privacy and data restrictions, could help identify vulnerable older people at the local level. The most vulnerable, however, will be likely to be those people living in the community yet to obtain a diagnosis and essential support. In some areas the diagnosis rates are as low as 38%. For this reason, it is critical that all health providers focus on increasing diagnosis rates.

The Dementia Enhanced Service can also play a key role in identifying vulnerable older people. The service ensures participating practices review their local populations for people who may be at risk of developing dementia. Participation in the Dementia Enhanced Service would therefore be a key lever in promoting identification of vulnerable older people.

3.2 Who do you feel is best placed to perform the role of a named accountable clinician in a primary care setting?

Having a named clinician responsible for the care of vulnerable individuals has the potential to transform the experience people with dementia have of health and social care. However, it’s crucial that the doctors and nurses who are assigned are accessible, understand dementia and how to provide the best care for people with the condition. The named clinician for vulnerable adults must be trained in dementia to effectively fulfil their role.

The Society also believes it is important to allow a level of flexibility for developing local, sustainable and cost effective solutions which serve the best interests of the local area. There may be local examples of effective accountable clinicians working outside of the primary care setting or individuals working in social care who may be better placed to provide this role than primary care clinicians.

For instance this may consider alternative providers to act as the named contact person. The National Dementia Strategy for England, Living Well with Dementia set out the need for ‘a Dementia Adviser (DA) to facilitate easy access to appropriate care, support and advice for those diagnosed with dementia and their carers’ (Department of Health, 2009).

Alzheimer’s Society offer Dementia Adviser services across various locations. The dementia adviser service is primarily for people with dementia, as well as their supporters and carers. It provides them with a named contact throughout their journey with dementia. The main aims of the service are to provide a quality information and signposting service which is tailored to individual need.
An evaluation of Dementia Advisers pilot in Worcestershire (La Fontaine et al, 2011) that people living with dementia experienced greater confidence in the availability of support, the opportunity to plan for the future including considering financial and care issues, information about local and county wide services and emotional support. The experience from organisations was also positive with participants noting increased joined up working and partnership working with services and agencies.

3.3 **Named clinician: providing a single, named contact to coordinate an individual’s care**

Please see comments under: Who do you feel is best placed to perform the role of a named accountable clinician in a primary care setting?

4 **Improving access: making it easier to book appointments and get advice**

4.1 **What are the barriers to introducing new technologies to improve access?**

Alzheimer’s Society believes that while there is value in introducing and looking towards new technologies, serious consideration needs to be given to the barriers that people with dementia face when using technology.

The Office of National Statistics reports that age has a sizeable effect on whether someone has ever used the internet with less than a third (30%) of those aged over 75 having used the internet (Office of National Statistics, 2012b). As dementia affects predominantly an older age group, it is likely that connection with others via the internet will play a very small part in their lives. This may also lead to isolation from information and services if they are provided as ‘digital by default’ (Cabinet Office, 2012).

Our report, Dementia 2013 found that 87% of people with dementia surveyed did not use electronic communication to connect with friends and family. It is critical that the introduction of new technologies does not replace the opportunity for face-to-face communication and personal contact, especially for older people living with dementia.

5 **Out of hours: ensuring a safe and consistent service**

5.1 **How can we best ensure clear accountability for out of hours services?**

There is a clear need for better information sharing on patient information across health and social care, including out of hours services. There have been issues in care homes where out of hours GPs, without knowledge of the resident’s dementia, have prescribed harmful anti-psychotics. These examples also demonstrate the need for comprehensive dementia training across all out of hours services.
6 Choice and control: providing clear and accurate information to help patients make decisions

6.1 How do you think patient choice can be supported in out of hospital care, for example more transparency, flexible provision and support for decisions?

Being able to make decisions and exert control over your life is a key factor influencing well-being. Yet, more than a quarter (28%) of people with dementia who responded to our Dementia 2013 survey said they were not able to make choices about their day-to-day life, and a further 7% said that they did not know.

Information and advice for people with dementia is an essential component of enabling choice and providing the best care. Lack of information and support for people with dementia, particularly immediately after diagnosis, is a frequent complaint (All-Party Parliamentary Group on Dementia, 2012). The Our Health website, developed in south-west England offers a comprehensive local service directory, along with performance indicators allowing comparisons between areas. This should be made available across England.

Choice and control would also be improved by supporting people with dementia to make decisions, and by respecting and implementing these choices when they are made. These principles are contained within the Mental Capacity Act. However, there still remains a lack of awareness of the MCA among professionals, as well as individuals and family members. Care home staff particularly lack confidence and often the MCA is not used for every day choices that maintain an individual’s identity, such as what to wear or eat. These factors must be addressed to support true patient choice.

6.2 What do you think are the barriers to enabling choice in out-of-hospital services?

Please see our comments under: How do you think patient choice can be supported in out of hospital care, for example more transparency, flexible provision and support for decisions?

7 Joining up services: sharing up to date and accurate information and supporting coordination of care

7.1 What do you see as the main barriers to achieving integrated out of hospital care and how can these be overcome?

Delivering integrated and personalised care is essential for people to live well with dementia yet the health and social care system is buckling under the pressure. Dementia is costing the UK £23 billion a year and over a third of these costs are borne by informal care from family members and other unpaid carers (Alzheimer’s Society, 2012b). It is clear that neither families nor the health and social care system can meet the demands of dementia alone.

Integrated care for a person living with dementia must start with a timely diagnosis. Without a diagnosis, people with dementia are unable to access the necessary support that could help them live well with the condition. However, even with the diagnosis, the current disjointed health and social
care system makes it difficult for people to access support. The issues of integration need to start with ensuring joint commissioning of services that stretches beyond health and social care. People with dementia still need appropriate and accessible information and access to services that are shaped around their needs, not a process.

Sharing of patient data between health and social care must be urgently addressed. Please refer to comments under: What do you think are the main barriers to data sharing between services to support patient care?

Our report, Building dementia-friendly communities: A priority for everyone demonstrates that truly integrated care must give greater focus to delivering community based solutions. People with dementia face both psychological and emotional barriers to being able to do more in their community, alongside physical issues. People with dementia also face significant barriers due to stigma or lack of understanding about the condition from the general public.

7.2 Do you have any examples of integrated out of hospital care happening in your local area and having a positive impact on patient outcomes?

Gnosall Medical Practice

Gnosall in the West Midlands is working to improve dementia diagnosis rates, as part of a wider project on dementia. In this project, a model in which services have been integrated into a single organisational entity has been developed, led by GPs who hire specialists directly.

As part of this model practice staff, known as Elderly Care Facilitators, are integral to improving the diagnosis experience. Gnosall Medical Practice provides a Memory Clinic and related services in-house. The arrangements bring the specialist expertise of psychiatry into the practice, and the practice retains clinical responsibility for patients.

Elderly Care Facilitators identify those who may need the service and then become champions for such patients. The facilitators are recruited from those with an existing enthusiasm and wealth of experience in health and social care but are local, knowledgeable and enthusiastic about caring for those with dementia.

They visit people suspected to have memory problems and do a structured assessment under the supervision of the consultants. They befriend and act as an intelligent companion and advocate for the patient and family. They also liaise with other practice staff, specialists and other agencies.

Circles of Support for People with Dementia, South of England

Circles of Support for People with Dementia is an approach that aims to reduce the need for paid support and promote people’s connections within communities.

Drawing together friends, family, neighbours, volunteers as well as paid staff, the Circle works with the person with dementia to think about what they would like to do in their life, and then supports them to make these things happen.
Everything developed in the project is highly personalised and suited to the individual. For example, individuals may be supported to take part in a local gardening group instead of attending a day centre, they can be introduced to new networks to create friendships or supported to progress interests such as computer skills.

People with dementia involved in the project are making and re-establishing connections more widely within their communities. For instance, one woman was unable to go to her much-loved singing group, following a move to a care home. Knowing that she was a regular churchgoer, one member of the Circle contacted the vicar who then made enquiries among members of the congregation who knew this woman well. A volunteer was found who was happy to accompany her to the singing group and she was able to join in regularly – meeting up with all her friends there again.

Early evaluations have found a critical need for flexibility. For some this has meant creating very informal Circles, being personal not prescriptive in their meetings, and tailoring communication to each participant in the Circle. With the project drawing to a close in March 2014, work is taking place to help dementia support workers, advisers and others who have been involved shape their practice in the future.

The National Development Team for Inclusion and Innovations in Dementia have been running pilots at four sites across the South of England:

- Mid-Devon, in partnership with Upstream
- Dorset, in partnership with Alzheimer’s Society Dorset
- Hampshire, in partnership with a range of voluntary and other organisations
- West London, in partnership with a range of voluntary and other organisations.

More examples of communities coming together to provide holistic and integrated care for people with dementia are available in Alzheimer’s Society report Building dementia-friendly communities: A priority for everyone (available at: alzheimers.org.uk/buildingdfcs)

7.3 What do you think are the main barriers to data sharing between services to support patient care?

It is clear that the lack of data sharing between health and social care settings represents a key barrier to achieving coordinated, patient centred care. It affects not only providers, but also commissioners and their ability to manage the local health population. In particular, Alzheimer’s Society has identified the following key issues with data sharing and integrated care:

- The Health and Social Care Act (the Act) has made sharing data sharing more difficult and the process is overly bureaucratic. Data protection legislation within the Act, has removed the ability for CCGs to access (and share) patient identifiable data. This is a key barrier to effective data sharing which ultimately benefits patients.
- Data is often incompatible between organisations and care settings. In addition to creating incentives to share data, consideration must also
be given to how organisations can make their data compatible for the broader system.

- Information for patients must be seen as service - as a mandatory component of patient care. This will also empower patients to more choice and control over their health and for professionals to tailored information more effectively to the patients needs.

- Commissioners do not have extensive population and individual level data available to inform commissioning decisions.

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