Responding to Changes in Dementia Care

Please note that the progression of dementia symptoms is rarely linear, and therefore 'stages' are very hard to define.

Every person living with dementia experiences their symptoms differently, and will have good days and bad days throughout their journey with the diagnosis. There can be moments or days within the early and mid stages where the person seems completely lucid and healthy, and other days where they seem to be struggling much more with their cognition. It is important to realise that several other factors can effect this – stress, hunger and thirst, fatigue, and so on.

On the whole dementia symptoms worsen very slowly over time. If there is ever a day where the person seems to have deteriorated very suddenly, it is important that the person be immediately referred to a health professional.

A sudden deterioration is much more likely to be 'delirium' – an acute state of confusion, disorientation, paranoia etc., due to one or more causes such as infection, medication toxicity, dehydration, constipation, or severe pain.

Throughout a person's journey with dementia, it is important to try and minimise hospital visits, as hospitals are very distressing places for people living with dementia. This is best done by ensuring:

- The person stays hydrated and clean to avoid Urinary Tract Infections and Skin Deterioration
- The person stays warm and comfortable to reduce risk of chest infections
- The person stays as physically active as possible to maintain physical health and avoid Skin Deterioration
- The person remains as socially and cognitively active as possible to reduce risk of depression and poor emotional / psychological health
- The person's environment is assessed re falls risks and Occupational Therapy input is sought as appropriate
- The person's medications are continually reviewed to avoid any unnecessary causes of delirium via medication toxicity

Early (Mild) Stage of Dementia

Common symptoms:

- Occasional short term memory loss
  e.g. repeating oneself in conversation; forgetting a particular meal has already been eaten

- Some struggles with language/communication
  e.g. muddles up words or can't find the right word;

- Struggles with concentration

e.g. looses track of a conversation and flows into another topic; struggling to keep track of a TV or book narrative

- Occasional moments of confusion and/or disorientation
  e.g. feelings of 'where am I?', 'why am I here?' – often accompanied by panic and also often hidden from others due to embarrassment

- Washing & dressing mostly independently, but some basic support needed with cooking, cleaning and/or taking medications
  e.g. verbal reminders of when to do things and how things work

Suggested Actions

a) Getting a diagnosis

Ensure that the individual has seen their GP so they are made aware of any concerns relating to cognition. Ideally a referral to a memory clinic will be made, and official diagnosis usually comes following brain scans.

Dementia is very difficult to diagnose, because:

- there are so many symptoms of dementia, and everyone experiences their dementia differently;
- many of the symptoms are similar with delirium and depression;
- people are afraid of dementia and can be very skilled at hiding their symptoms
- brain scans don't always show up damage in the early stages, and verbal/written tests are too easy for some people to pass

Referral waiting times to Social Services, Memory Clinics and specialist clinician (e.g. geriatrician) vary hugely depending on where the person lives, so it is good to note any and all concerns with the GP as early as possible.

b) Finding light-touch support at home

Source at-home care or 'creative befriender' support, for example someone to visit for 2 hours a few times a week

- Private carers offer greater flexibility in shift patterns and role description with better continuity of care, at a lower cost than using an agency.
- However, agencies offer rota management (i.e. if usual carer is on holiday/off sick), complaint procedures and training.

It would be a good idea to check upfront whether the private carer is able to increase their hours as the person's needs/dependency increases. Many private carers and agency provision will be either live-in or live-out, which may mean that a new carer will need to be found in the future if you're seeking a live-in role in the future

Getting a carer in at this early stage may seem premature, but it allows for:

- A detailed care plan to be created while the individual is able to clearly articulate their needs and wants
- The individual to get to know someone who will be able to step up support in response to their dependency level (i.e. consistency of care)
- Any problems the individual is having to be quickly flagged up and managed effectively, which can slow down the rate of deterioration and prevent crises

You can expect to spend around £10 - 20/hour for private care and £18 - 30/hour for agency care

Finding a private carer can be tricky, and it often starts with word of mouth. Do you know anyone else that has had care at home that was highly regarded? Even if that connection is via an agency, the carer may know others that practice privately.

Following this, one can place a hard copy advert on local community boards (supermarkets, cafes, community centres) or a digital ad in local platforms (e.g. www.nextdoor.co.uk, FaceBook, and Gumtree).
NB only include anonymised/general information in the ad, for example:

- main caring tasks - e.g. companionship, help with brushing teeth
- key requirements of carer - e.g. gender, language, fitness level, matching hobbies and interests
- area/town that person with dementia is living in
- remuneration.

There is no reason to include personal details at this point.

Finding a care agency will be simple – there are many – although there will be a longer process before hiring. The agency will want to carry out an assessment of the person needing care, and a risk assessment of their home environment. There will be several documents to go through and sign, and it may take several days or weeks before a carer is found that fits the person's preferred profile.

There may also be some difficulties in ensuring that the same carer that visits. (Ideally you want the same person for relationship building).

A very quick way to find an agency is to google "home care + name of town" or search via the CQC website, https://www.cqc.org.uk/

There will be several results, usually ranging from large national organisations through to small, local, family-owned providers.

Always check the CQC rating of a registered care provider first, using and ensure the service is rated 'Outstanding' or 'Good.'

Attitude is by far the most important element to get right in a carer. While experience – and ideally experience with people living with dementia – can of

course be hugely beneficial, the tasks and roles within care can be demonstrated by family members, and one could even pay for the carer to go on a training course if preferred. But no training can instil a caring, patient, empathetic, dedicated attitude.

With both agency and private carers, you don't need to settle for the first person you meet if personalities and/or skills do not match

c) Registering a Power of Attorney (POA)

We would suggest that everyone have a Power of Attorney, regardless of diagnosis, to ensure that their later life and end of life wishes be respected. POAs can be responsible for decisions relating to Health and Welfare, or Property and Financial Affairs. Registration can take several weeks, so it is better to get this in place while the person has capacity to consent to this and discuss with their POA and others what their wishes are for their future

The cheapest way to register a POA is via the government website: https://www.gov.uk/power-of-attorney

When one applies for POA status, there is a choice between having it activated immediately, or activated later following a clinical assessment of mental capacity. We would suggest that having it immediately active reduces paperwork and effort later down the line – especially as the person themselves will remain in full control over any decision while they have capacity to make it

Mid (Moderate) Stage of Dementia

Common Symptoms:

- Regular Short and mid-term memory loss
  e.g. frequently completely forgetting events within the last few hours and days, and sometimes forgetting events from months and a few years back; regular repetition in questions and stories; struggling to recognise people by name

- Frequent difficulties with language/communication and concentration
  e.g. regularly struggling to speak, write and read, often causing much frustration; non-verbal communication remains intact

- Regular experiences of confusion and/or disorientation
  e.g. frequently not understanding what is going on around the person, often causing much anxiety, anger and/or distress

- Some support needed with washing & dressing, some to full support needed with cooking, cleaning and/or taking medications
  e.g. verbal prompts; some practical interventions such as laying out clothes for the day, putting toothpaste on the toothbrush, making meals so person can just access ready-to-eat food, managing the administration of medications

Suggested Actions

d) Increasing the care support at home

Care will now be needed on a more regular basis – perhaps a few hours every day – and you may even find that having a live-in carer is more beneficial, especially if early mornings or the overnight period involves some difficulties for the individual

Again, full-time and live in carers can be sourced privately or via an agency (see above section)

e) Close liaising with health professionals and social services

Continue to update the GP and Social Services as symptoms progress. They may wish to may house visits if that is easier for the individual, along with an Occupational Therapist (OT) who can ensure the home is as safe and comfortable for the individual by way of specialist designs and assistive technologies

Another useful referral may be to a Physiotherapist (PT). PTs specialise in keeping the person physically fit and healthy by way of exercises and stretches.

Both PTs and OTs can also be sought privately, if you wish to avoid the waiting time on the NHS. It will then be important to forward all assessments back to the GP for their general health records.

f) Explore alternative housing options for future needs

This stage would be the best time to seek out 'Housing with Care' options, if in line with the person's wishes (and with full consent of the individual if possible).

'Extra Care' Housing includes:

- Sheltered Housing / Care
    - 24-hour security
    - Assistance with daily living including medication management, bathing and dressing.
    - Bought or rented
    - Private or state via local council or housing association
    - https://www.which.co.uk/elderly-care/housing-options/sheltered
- Assisted Living
    - Independent living in a specialist complex
    - Facilities differ in terms of what they offer, but usually provide nurses and care staff to attend at any given time.

- Choose how much or little you participate in optional communal areas and activities
- https://ukcareguide.co.uk/assisted-living/

There are also 'Retirement villages' which includes anything from an estate to a full village-sized development – including a combination of bungalows, flats, houses, care homes and/or extra care housing. Most larger villages include leisure & hobby facilities, restaurants, shops, hairdressing salon, etc.
http://www.housingcare.org/jargon-retirement-village.aspx

People that require higher levels or specialty care may need to live in a care or nursing home. Nursing homes include medically qualified nursing staff – implying higher needs of residents.

Care and Nursing Homes can range from large national for-profit organisations through to small, independent charities. There are a huge variety in the style; staff ratios, backgrounds and training; size; and location (urban vs rural). Just because a home *looks* fantastic, doesn't mean its quality of care is good.

We suggest that you visit the home, chat to the manager, some residents, and to other relatives if possible.

Best practice in dementia care is called Person Centred Care, meaning the residents are at the heart of all care practice. It is (or will be) *their* home after all, not the staffs'!

Some example indicators of person centred care include:
- Residents can have the drink of their choice whenever they are thirsty (not just at a designated 'tea time')
- Bedrooms are homely and decorated individually with personal items and furniture
- Residents are in several different spaces across the home, doing several different activities. For example, some may be sleeping in a quiet area, some may be in their rooms, some watching an appropriate show on TV, others out in the garden, and there may be group activities also ongoing such as chair exercises and arts & crafts. What you don't want to see is almost all residents sat around the edge of one living room with two TVs showing Jeremy Kyle.
- Staff call each person by their preferred name (so that one might be addressed as Professor, another by their first name, and another as "sweetpea")
- Staff know the life story of each resident and their preferred activities, hobbies and interests
- Staff firmly believe that all behaviour has a cause. This means that if someone is agitated / aggressive the staff will try and understand why that might be so that they can support the person to feel better, rather than dismissing the behaviour as "just because of the dementia."
- Happy staff! If staff feel loved they are much more able to provide loving care to their residents. And this usually translates into low staff turnover and sickness rates

Ideally, one could arrange for the person himself or herself to visit for the day, or to have a few days respite care in the home to see how they respond to the staff and environment.

The person with dementia may have physical health needs that require qualified nursing staff. This is the distinction between a 'residential' and 'nursing' care home. Unfortunately not every carehome has the same criteria for residential versus nursing support, as it will depend on the person's diagnoses and how reliable the carehome's local district nursing staff are.
The home will carry out a pre-admission assessment to establish whether they can meet the person's needs.

Expect to pay between £25 - 52k / year for residential care, and £30k – 80k / year for nursing care

Late (Severe) Stage of Dementia

- Almost no short or mid-term memory
  e.g. person lives very much in a state of 'now' with little factual memory of past except for childhood, and little ability to comprehend the future; not recognising loved ones and/or muddling up younger generations with their older relatives. NB the emotional memory often remains intact – the person may not know your name or their relationship with you, but may still recognise a sense of love and trust

- Considerable deterioration with language/communication and concentration
  e.g. little ability to communicate verbally, may use sounds instead of words; little or no ability to read or write; non-verbal communication often remains intact

- Regular experiences of confusion and/or disorientation
  *e.g. very little understanding of what is going on around the person, often causing much anxiety, anger and/or distress which combined with deteriorated communication skills can be easily mis*interpreted as meaningless aggression*

- Full support needed with washing & dressing, cooking, cleaning and/or taking medications
  e.g. supervision and guidance throughout all Activities of Daily Living (ADLs) via verbal prompts and practical intervention

- Some to full support needed with continence management
  e.g. person's body may 'forget' how to control bladder and/or bowels, so that pads will need to be worn and changed regularly

- Other physical health problems may require qualified health professionals

e.g. dementia rarely occurs as the only diagnosis in old age, and it can exacerbate other diagnoses, just as much as other diagnoses may exacerbate the dementia

Suggested Actions

Live-in care (at home) will be necessary at this stage.

Depending on how happy the individual is to have help to wash and dress, and how physically well they are, you may need to find additional carers for occasional hours of support with certain activities, throughout the week

Similarly if the individual is struggling to sleep well and is at high risk (eg from falls) during the night, a live-in carer may need additional support from a 'waking night' carer (a carer who will be awake throughout the night)

If the individual's health needs are so high that they require qualified (nursing) staff, you may need to employ private nurses to live-in and or regularly visit. NHS community teams (eg "community matrons", "district nurses" and "community mental health") rarely support past a certain level of dependency, and will likely advise nursing home admission in communication with Social Services.

Full-time nursing support at home costs around £150k/year. Nursing homes cost < £80k/year.

A formal 'Best Interests Meeting' would ideally be held and minuted (with all key people involved in the individual's health and wellbeing) to establish whether the person would be safer and more comfortable in a purpose-built nursing environment (ie nursing home) or their own home, adapted. There are of course pros and cons on each side.

Some people with complex healthcare needs are eligible for *NHS Continuing Healthcare* – which provides free Social Care. The person will be assessed by a multidisciplinary team of healthcare professionals across the full range of areas of need. To apply for NHS Continuing Health Care here: https://www.nhs.uk/conditions/social-care-and-support/nhs-continuing-care/