



Department
of Health

A manual for good social
work practice

Supporting adults who have
dementia

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Foreword from Lyn Romeo, Chief Social Worker for Adults

The Prime Minister's Challenge on Dementia 2020 builds on the achievements of the Prime Minister's Challenge on Dementia 2012-15 and aims to identify what needs to be done to ensure that dementia care, support, awareness and research are transformed by 2020.

These challenges will require social workers to keep up-to-date about how practice for people living with dementia and their carers can be further improved. Social workers are increasingly at the forefront of developing asset and strengths-based approaches to working with people across adult social care, preventing and delaying the need for services and ensuring resources and support are in place –this places an ever greater emphasis on their ability to lead across and beyond their professional boundaries, working with the person, their carers and communities to achieve the best outcomes, including enabling citizenship and inclusion.

Legislative changes, such as the implementation of the Care Act 2014 and increased requirements relating to Mental Capacity Act judgements, are also increasing demands on social workers in their practice with people who are just beginning to experience the effects of dementia or related conditions and their families and carers.

Organisational change within the NHS such as that being driven by the "5 Year Forward View" and the Secretary of State for Health's priority to transform out of hospital care, including "7-day working" for the NHS, also affect the reality for social work practice with people and communities.

As a result, in 2014, I commissioned the College of Social Work to work with the sector to develop practice guidance for social workers working with people with dementia and other cognitive impairments, with the aim of improving the quality of practice in this crucial area.

As our knowledge and awareness of dementia increases, social workers need to be up to date with practice in relation to dementia, not just within social work but developments and innovation across the wider health and social care landscape. I welcome this guidance as a valuable resource for all social workers which will further raise the quality of professional social work practice.



Lyn Romeo

Chief Social Worker for Adults (England)

1. This practice guidance

This manual is designed to assist its readers with the very practical and sometimes complicated issues that they may experience in their practice with adults who have different types and stages of dementia. It aims to assist the reader reflect on what they do know, start to fill the gaps in the areas that are new to them and is a resource directory for the reader to use and inform their practice in supporting people living with dementia.

This manual is not designed to focus specifically on high risk, nor safeguarding work (where you should follow your own organisation's safeguarding policies and procedures).

Who is it for?

This resource is targeted at social workers in day-to-day practice supporting adults who have dementia, as well as their carers, families, friends, etc. It is also for senior social workers, as well as social work supervisors and managers who may dip in and out of social work practice with adults who have dementia.

Why has it been written?

The number of people with dementia is increasing rapidly every year. In 2015 there are approximately 850,000 people in the UK living with dementia. By 2025 it's estimated that will increase to around 1 million. Although training materials exist for multiple professions, especially health staff, there is a conspicuous absence in terms of specific resources to help social workers.

The Department of Health commissioned TCSW to produce this learning resource for social workers who work with adults who have dementia (and their carers, families).

Who wrote it?

This manual has been written by The College of Social Work's (TCSW) Professional Practice Team. TCSW ran a number of workshops around England in early 2015 to help identify priorities and helpful resources invited a cross section of participants including social workers, carers, adult social care managers, voluntary sector agencies, charities, academics, learning and development officers, and dementia experts. This resource has been informed by the workshops and subsequent feedback from participants on the drafts.

How to use

Dementia Core Skills and Knowledge Framework (March 2015)

The Dementia Core Skills & Knowledge Framework was commissioned by the Department of Health and sets out the core skills and knowledge which would be transferable and applicable across different types of service provision. It includes expected learning outcomes for training delivery, key policy and legal references and is aligned to related national occupational standards. The aim is to help ensure the quality and consistency of dementia training, and to help prevent unnecessary duplication of training.

The Core Skills & Knowledge Framework is structured in three tiers:

Tier 1 – dementia awareness raising, in terms of knowledge, skills and attitudes for all those working in health and care;

Tier 2 – knowledge, skills and attitudes for roles that have regular contact with people living with dementia;

Tier 3 – enhancing the knowledge, skills and attitudes for key staff (experts) working with people living with dementia designed to support them to play leadership roles.

This resource does cover all of the requirements set out Tier 1 and most of the Tier 2 learning outcomes. It does not try and cover all as the resource priorities those areas that social workers told us were of most importance to them.

Self evaluating your knowledge and practice

NES/SSSC in 2011 produced a framework paper that sets out levels of Knowledge and Skills specific to the knowledge, skills and behaviours specific to the worker's role in relation to dementia. Rather than being hierarchical, the levels are concerned with levels of responsibility in relation to working with people with dementia which will vary greatly across organisations and sectors. Each level defines the expertise, specific to their role in relation to dementia, that a worker must have, rather than in relation to their seniority within the organisation or their profession.

http://www.nes.scot.nhs.uk/media/1523859/promoting_excellence.pdf

(please note that the paper is for Scotland and Health Education England have similar tiers for training for NHS staff in England).

- The 'Dementia Informed Practice Level' provides the baseline knowledge and skills required by all staff working in health and social care settings including a person's own home.
- The 'Dementia Skilled Practice Level' describes the knowledge and skills required by all staff that have direct and/or substantial contact with people with dementia and their families and carers.
- The 'Enhanced Dementia Practice Level' outlines the knowledge and skills required by health and social services staff that have more regular and intense contact with people with dementia, provide specific interventions, and/or direct/manage care and services.

- The 'Expertise in Dementia Practice Level' outlines the knowledge and skills required for health and social care staff who by virtue of their role and practice setting, play an expert specialist role in the care, treatment and support of people with dementia.

You may wish to use the statements to self assess where you are now, identify the gaps, and develop a plan including the use of this resource as to how you might address some of those gaps.

Values informing practice

The over-arching ethos of the Care Act 2014 is embedded in this resource. There is deliberate emphasis upon person-centred, strengths-based social work which is in keeping with the clear message from the workshops about working towards and with people's strengths and abilities. Social workers practice should be in keeping with an ethical value-base, but also with the principles running through the Care Act and its statutory guidance, which is why each section identified the relevant Care Act principles.

2. A person-centred approach

“Person-centred dementia care is about understanding and responding to the person with dementia as an individual. It involves considering the whole person, taking into account not just their health condition, but also each individual’s life history, unique abilities, interests, preferences and needs. It is about building relationships with people with dementia and their family carers, putting them at the heart of decision making – ensuring the person is an equal partner in their health and care.”¹

This unit sets out the implications for supporting people with dementia and considers issues for assessing; communicating, working at a pace which is right for the person and using the persons social networks appropriately. Person centred refers *“to a family of approaches aimed at enabling people who use services to plan their own futures and to get the services that they need. While the terminology varies between different user groups, the fundamental values of the concept are the same – embracing the principles of independence, choice, inclusion, equality and empowerment as the foundations of service provision.”* (Dowling et al 2006)²

Assessing

“The assessment is an opportunity for you to tell us about the difficulties you are facing, and to discuss positive ways of dealing with them.” (Croydon Council website)

The quote above captures part of the task of assessing. To do it well, in a manner that is meaningful, and person-centred, you must master the basics. These include thorough assessment, alongside good communication and relationship-building skills (looked at in more detail below).

Take a look at this clip from the SCIE dementia gateway.

<http://www.scie.org.uk/socialcaredtv/video-player.asp?v=gettingtoknowthepersonwithdementia>

You must be able to create an environment of trust and safety which allows the person to share their concerns without “fear or favour” which means before you start you need to be mindful of the setting in which you assess and how conducive it is. Have you ascertained what would work for this person in terms of location, amount of noise, light etc? In most cases it’s likely to be a calm, quiet space.

¹ Dementia Core Skills & Knowledge Framework 2015 Health Education England.

² Person-centred planning in social care A scoping review (2006) Sandra Dowling, Jill Manthorpe and Sarah Cowley in association with Sarah King, Vicki Raymond, Wendy Perez and Pauline Weinstein JRF.

Good assessment requires an approach which is holistic and is strengths based. This means you need to identify and include what the person likes doing, what they are good at, what is important to them. You should consider co-producing positive statements by celebrating what is still possible, what the person can still do, while ensuring their dignity is central. In assessing you should be able to identify the things/goals the person wants to achieve. There can be a challenge here in terms of how you try to reconcile the desired goals of the person with the perceptions of yourself and/or their carers as to what is achievable. This can be common when someone has a dementia.

Being person centred means that you recognise people and their carers come with a range of expectation, perceptions and anxieties. You are able to manage their expectations, provide reassurance where that is possible and be honest in managing the many uncertainties (about care, finance etc.). It is also about how you discuss and support positive risk-taking, enabling the person to live as freely as possible.

An obvious point but one that needs to be emphasised is “Whilst assessing you should not presume anything.”

Assessment is not a one-off process and in relation to dementia, social workers need to think about how care plans are implemented. Attempts at phased changes and taster sessions with different activities or services will allow the person to maintain autonomy, with what support feels right for them. How have you communicated the plans to carers and have they understood the rationale as well as the specifics?

Similarly you need to plan how you end your involvement with the person. What is going to be appropriate for this person, does it need to be phased? You need to be clear on why you are finishing your work, what happens next, who they can contact about what, and they should be advised about how and when to re-contact your service in the future.

Communication skills

Social workers should be honest with those who have dementia and their families. You should be open about what you can and can't achieve within the boundaries of your job. You need to be open about how dementia is described seeking and using the person's own definition.

Do not assume the person can not communicate or comprehend, even with a mid-stage or late stage dementia. Avoid using jargon, acronyms, abbreviations, and the day-to-day work language social workers sometimes forget might be frightening for others outside this field. Take into account that the person and their carer may have levels of anxiety and distress when trying to communicate with you. Remember this can mean the person may need more time to understand what is being asked. The Dementia Project have a useful blog about this <http://dementiaproject.net/blog/?p=189>. Try not to leap in with answers – be comfortable with the silence which may be a necessary part of them getting to the point where they can find the right words to respond to your questions. It's ok to wait. You may need to use pictorial aids to communicate. It is important you find ways to help the person communicate even if this may be at a limited level.

You need to be mindful of how you describe things, for example, 'end of life' may make sense rather than 'palliative'. Consider appropriate descriptions like 'latter years' (there may

be many). Clarity is key, and means avoiding medical assertions if they are unhelpful. Phrases like ‘personal care’ may be meaningless – be specific and talk about ‘washing and dressing’, ‘using the loo’, ‘cooking and eating’.

Be prepared for staple responses when the person is misunderstanding your question. Try closed questions which they may feel better able to answer.

A lot of people with dementia happen to be older and so you may need to consider if there are hearing or sight impairments which impact on the communication. Also, see unit on types and stages regarding terminology of dementia. In doing so it is important to remember that the person with dementia and their carers may sometimes cover up their lost abilities. One therefore needs to demonstrate sensitivity for the person’s sense of self-worth, deploying active listening skills, an empathic approach, and consider, in an appropriate way, sharing something about your own identity (in a professional way) to achieve a sense of transactional balance. It’s ok to be human, you must not underestimate the value of warmth and compassion in your communications with the person, it does not lessen your professionalism – it enhances it.

Pace of work and length of relationship

Not only is it important to go at the person’s pace, but a person-centred approach means ensuring the person does not feel rushed. It requires you to make sure you take time to reflect on your practice and consider what is going on for the person, their carers and family, and in their wider social world. It means making sense of what is happening and understanding that at whatever stage the person with dementia is at, be it pre or post diagnosis, they will need time to process what they are experiencing. It means that you are able to recognise and work with a degree of resistance or denial from the person or their carers.

Working at a person’s paces mean you need to be assertive in ensuring you have the right amount of time with the person to build rapport. The person needs to feel they can trust you too. This requires you to have confidence in your own practice and be able to assert the validity of your own conviction. It includes justifying the need to invest the time that is required for the person’s desired outcome. The more time invested in early stages, the better the relationship between you and the person, the more likely the outcome will be person-centred and avoid unnecessary interventions in the future. You may want to point people to the “This is Me” resource <http://www.alzheimers.org.uk/thisisme> and to support them if appropriate in completing it, as it provides a useful focus for setting out their needs, preferences, likes, dislikes and interests.

It’s also important to remember a holistic assessment should also include time to watch and observe the person and how they interact with others.

Assessment is not static and the nature of dementia does mean there will be changes over time which will require you too adapt your approach over time to accommodate this. It means you will need to manage the tensions between current models of service which tend to focus on present need and the need to provide services which adapt and change to the change in the person’s conditions.

The person's support network

Meaningful social work with dementia involves³ working alongside family, carers, and friends. You will have to be able to co-ordinate appropriately and respectfully and use skills of diplomacy accordingly.

Remember that an adult with an early stage dementia may want to expand their own (pre-existing) support network. This assets and strengths-based approach should be your starting point. IRISS have published a useful paper setting out what strengths based approach is <http://www.iriss.org.uk/resources/strengths-based-approaches-working-individuals#content>

A person may want to connect with others by attending groups (eg. Peer support, mentoring groups etc) or to engage via technology using web based forums, blogs social media etc).

You may there are disagreements in the network, you will need to be able to assist people experiencing shock and other emotions. This might also bring into play the need to de-escalate difficult situations, keeping the person at the centre and ensuring they retain as much control as possible.

You will need to know your boundaries around confidentiality but also when to refer to more specialist teams. Family dynamics may be in the mix and various differing agendas. Social workers told us that in practice, they felt it was important not to take everything at face value and to give consideration to any gender, race, sexuality, disability and age issues.

You should be able to explain and interpret the different manifestations of dementia to the person's loved ones, for example, the person may start having problems sequencing (following the order of things). This is so that those supporting can provide the sort of help that enables the person to carry out the tasks they can still manage themselves. You might need to educate others (including family and carers) around body language and how this might be perceived by the person. The behaviour of those around the person, verbal or otherwise, will have an impact for them. You should be able to judge when your social work educative role is required.

Exercise/learning activity:

1. How do you currently communicate with people who have dementia?

What might you do differently?

Which of your social work skills do you need to develop to communicate with someone in the later stages of dementia?

2. How do you evaluate the success of your communication skills?
3. How do you seek feedback from the person and their carers?

³ With the person's agreement, depending upon whether you are in the realms of completing a [Mental Capacity Act \[2005\]](#) assessment.

3. Types and stages

Recent Alzheimer's Society research shows that 850,000 people in the UK have been diagnosed with a form of dementia. By 2025, this will hit a figure of 1 million. These are of course those with a diagnosis and doesn't include the other adults who, for various reasons, are undiagnosed. A lot of these individuals will be cared for by partners, relatives and or friends. Increasing life expectancy with what is regularly a condition appearing in later age dictates the need for social workers to be able to work positively, productively, and collaboratively with adults who have dementia to assist in achieving the best autonomy and life quality possible.

Start with the person

As noted in the previous unit, understanding what the person with dementia is going through and how they are feeling about it all is the first and most important part of your work. You need to be realistic with them about what is happening, what's ahead, what it means, in the here and now. Films such as "Still Alice" provide a helpful starting point alongside the stories and commentaries of people living with Dementia such as The Me In Dementia. Dealing With Diagnosis: <http://www.nhs.uk/conditions/dementia-guide/pages/alzheimers-diagnosis-real-story.aspx>

Acknowledging the impact of their dementia is key. It will be different for everybody, whatever the severity. To do so you need to be able to explain to them (and, if appropriate, their carer/family/network) what progression of the disease would look like and mean in terms of care. In doing so a key part is creating reassurance and certainty for the person as far as possible. You should think about pacing information-giving by being guided by cues from the person and their carer over how much they want to know. Reassurance will also be achieved if you can make suggestions about what the person can do to achieve the best quality of life. It goes without saying that you need to be mindful of how you communicate avoiding medical, and professional terminology, especially towards the end of someone's life.

Types of dementia

Social workers contributing to this resource told us they can not be experts in understanding types and stages of dementia with adults, nor should they be expected to be. However, you should have a reasonable knowledge of the most commonly diagnose forms:

- Alzheimer's (the most common type).
- Vascular dementia (may occur after a stroke).

- Lewy Body (nerve cell deterioration, accumulation of lewy bodies in the brain).
- Fronto-temporal, (lobe degeneration – can affect personality and behaviour).
- Korsakoff's Syndrome (commonly caused by long term alcohol misuse).
- HIV-related (sometimes as a result of late diagnosis & non treatment).
- Parkinson's Disease.

Good starting points for specific information about each of these can be found at:

- Alzheimers Society:
<http://www.alzheimersresearchuk.org/about-dementia/types-of-dementia/>
and
<http://www.alzheimers.org.uk/site/scripts/documents.php?categoryID=200362;>
or
- SCIE's dementia gateway:
<http://www.scie.org.uk/publications/dementia/understanding-dementia/about.asp>
which has a range of articles and e learning tools

You need to understand the different types, but also the different impacts they have and the way they progressively impact on the person. The Alzheimer's Society. Dementia Brain Tour <http://www.alzheimers.org.uk/braintour> provides a helpful set of video clips to help you.

There are different issues, manifestations, symptoms and expectations regarding different types of dementia. Its important to understand that some adults have more than one type of dementia, known as 'mixed dementia'.

https://www.alz.org/dementia/downloads/topicsheet_mixed.pdf

Some people will also have to deal with "dual-diagnosis", ie when they have dementia in addition to another known medical condition which may introduce difficulties for them in staying well. Having a sophisticated grasp of how dual diagnosis might make life harder is important, for example, an adult in later life with dementia and autism will have specific needs that will need to be assessed and understood before any planning on how to meet these needs (see [A Manual For Good Social Work Practice Supporting Adults Who Have Autism.](#)) Be aware that many people who are diagnosed with dementia will be living with at least one other long-term condition either at the point of diagnosis or in the future. Dementia rarely manifests in isolation.

You should be aware of conditions that can sometimes be mistaken for signs of dementia, for example urinary tract infections sometimes referred to as UTI's (common in older adults), depression or brain injuries. You should ensure health conditions such as these have been ruled out before assuming the person has dementia and also be aware that as a consequence of a singular episode of poor health, people can be frequently labelled as having dementia without any evidence, tests or formal diagnosis.

Stages of dementia

There is well documented evidence that dementia has a recognised pathway of progression and the needs of a person with dementia, and their family and carers will be different at different stages of the condition. One might consider the stages to be:

- Keeping well, prevention, and finding out it's dementia.
- Living well.
- Living well with increasing help and support.
- End of life and dying well.⁴

We have covered early stages of dementia and working with this in the third unit, 'Early Intervention'. In the chronology of a person's dementia, the phrases 'early stage' or 'mild dementia' are usually used for adults in what is the traditionally recognised 'working age' period of their life (up to around 65 years of age), in keeping with historical retirement rules. It's important you are able to differentiate between the stages and levels of dementia with the person, and apply your different levels of knowledge in your practice accordingly. Be clear on terminology – there are differing views and uses, and 'early onset' can mean a number of things with regard to dementia and its severity.

In particular, you need to have a good grounding in being able to spot the early signs of dementia. The SCIE dementia Gateway provides a good set of resources on this.

<http://www.scie.org.uk/publications/dementia/understanding-dementia/diagnosis/index.asp>

You may be the first person to have contact with the person and it is therefore important that you are able to provide the reassurance and information for someone early on.

Bear in mind that some individuals will be keen to gain a diagnosis, but not all will. Similarly, as a person's dementia is progressing, regular reviews of need will be required. A useful source for understanding the later stage of dementia is the Alzheimers Society web page:

https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=101.

Latterly, you need to feel confident about when to bring in a dementia specialist into the picture. The word 'referral' or 'refer' can frighten, confuse and exclude those with dementia and their carers. Be confident to explain when you have a role to assist and when you feel someone with different or more specialist skills might be a more suitable co-ordinator, for example, a dementia navigator, Admiral Nurse, third sector support worker or a GP. You need to know what resources are available in your area with this regard.

Early onset dementia

Currently most people diagnosed with dementia are over the age of 65. However there are a growing number who are diagnosed at an early age. There may be an additional set of issues that can arise for that group such as coping with employment, childcare. The following resources can provide you with some insight into these.

⁴ NES framework for dementia.

- The charity Young Dementia is a good starting point.
<http://www.youngdementiauk.org/>
- The following audio clip provides a good grounding on early onset:
<http://www.npr.org/2011/08/24/139918752/diagnosing-and-living-with-early-onset-dementia>
- Blog about the characteristics:
<http://dementiaproject.net/blog/?m=20140620>
- Info:
<http://www.alzheimersresearchuk.org/about-dementia/types-of-dementia/alzheimers-disease/early-onset-alzheimers/?gclid=CMPFmpHjzcUCFWvHtAodIBUAQw>
- video clip:
<http://www.scie.org.uk/socialcaretv/video-player.asp?guid=61aa9350-6c43-4098-bb5d-1c0ee733f3c7>
- pdf on it:
http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1766

Multiple social work approaches:

There are a number of approaches to supporting people with dementia. You are encouraged to access training programs (including e-learning, see resource below) available for health professionals and colleagues in other fields related to working with dementia to expand your own awareness and ensure your knowledge of dementia is sufficient. Our understanding of dementia is increasing and it is important that you are able to maintain the currency of your knowledge.

The social work task

Your role as a social worker needs to change and adapt to the changing needs of the person, family and/or carers. You will need a variety of strategies for social work with dementia. By researching methods of social work which may help, in conjunction with your conversations with the person and their network, you should be able to discuss and support behaviours that change over time. While doing so, you should retain the positive, strengths-based approach around living well with dementia, and helping the person to maximise their quality of life. You need to focus on getting the person and their carer to remember that they can live well with this condition.

Using a timeline

One helpful model suggested by some specialist social workers is using the concept of timelines. Social workers have commented that picturing a time continuum with the person can be helpful. You should attempt to link this approach with how someone's life in the future links into their lifestyle, hobbies, interests and preferences. You should be able to walk the person through the understanding of typical progression (if they want to know) over time and link it to their current/projected health, what might be typical, in association with concepts

of loss further ahead. Being mindful and sensitive over timing and readiness of these sort of conversations is important – you need to judge carefully how ready the person and their carer is around these topics of conversation.

Preparing for the end of life

With failing health a key role is in enabling a person to consider important and sensitive questions about how they'd like to be cared for, and ultimately what plans they want to make for their will etc. The starting point is around capacity and you therefore need to have a good knowledge of the Mental Capacity Act 2005 (Link to be inserted to mca resource).

You need to be familiar with:

- Lasting Powers of Attorney. This is a legal tool that allows an individual to appoint to make certain decisions on their behalf. There are two different types of LPA: property and affairs LPA and health and welfare LPA. Each type covers different decisions and there are separate application forms for each.
- Advanced Decisions/Living Wills: An advance decision (sometimes known as an advance decision to refuse treatment, an ADRT, or a living will) is a decision you can make now to refuse a specific type of treatment at some time in the future. It lets family, carers and health professionals know whether the person wants to refuse specific treatments in the future. This is so that they will know the individuals wishes if they are unable to make or communicate those decisions yourself. NHS Improving Quality have useful information that can be found at: <http://www.nhs.uk/Planners/end-of-life-care/Pages/advance-decision-to-refuse-treatment.aspx>
- Do not resuscitate agreements – tend to be part of advanced decisions. Further detailed information can be found at the advanced decision to refuse treatment website <http://www.adrt.nhs.uk/index.html> including a helpful leaflet for individuals.

You should be able to assist the person to get any processes underway whilst they have capacity to make their care decisions. You will need to be up-to-date on the current thinking on fluctuating capacity, and case law rulings in this area (see TCSW Curriculum Guide For MCA for this).

Learning plan:

- Which of these practice areas do you feel confident in?
- Which areas do you need to improve through your own CPD and how will you do this?

Exercise/learning activity:

- What language might you use when asking a person how dementia has changed their life?
- Will it differ with someone whose dementia is new, compared with dementia which is advanced and how?
- How can you ensure diagnoses are valid? With whom will you check?

- In a group, list what might be early signs of dementia for adults different age groups with different health conditions alongside dementia. How do they vary? How might this change your practice? Should it?
- Which social work theories will you consider when working with an adult with dementia and why? Lifespan development? Loss?

4. Early intervention

Introduction

The Care Act sets out the Wellbeing principle with the statutory guidance requiring “Local authorities [to] promote wellbeing when carrying out any of their care and support functions in respect of a person.” (1.2)

The statutory guidance goes on to recognise *“the importance of preventing or delaying the development of needs for care and support and the importance of reducing needs that already exist. At every interaction with a person, a local authority should consider whether or how the person’s needs could be reduced or other needs could be delayed from arising. Effective interventions at the right time can stop needs from escalating, and help people maintain their independence for longer”*. (1.14c)

This unit focuses on what this means in practice when you are supporting a person with dementia.

- Being vigilant of the early stages of dementia, being able to spot ‘early signs’.
- Creating and maintaining good inter-agency relationships.
- Understanding and navigating systems on behalf of others.
- Advance-planning.
- Multi-disciplinary working.
- How you can develop your professional leadership skills.

Preventative, pre-emptive work

As the Care Act guidance states, one of the social work tasks is about how you support people in preventing deterioration in their physical, psychological and social health and how you enable individuals to thrive and have the best quality of life for the longest possible length of time.

The NES guide notes that *“A person with dementia frequently enters into a long ‘flat’ period after diagnosis because of the belief that little will – or can be done – for them in these early stages. In fact, the potential for help through early intervention is high. Early intervention – including providing good information, support and care – is designed to help a person with dementia deal with the challenges of their diagnosis and to aspire to a meaningful and positive life. There is a clear and prolonged window of opportunity for health and social care*

professionals, third sector and other support services to play an important role in making early intervention a reality.”⁵

This means you could be involved with the person at a point where they are requiring assessment either before or close to them receiving a diagnosis. The earlier the better, so as to complete some investment in the early stages of their health changing. You need to be able to have a reasonable knowledge on what might be the early warning signs that a person may have dementia. A good source of knowledge can be found on the SCIE Dementia Gateway: <http://www.scie.org.uk/publications/dementia/understanding-dementia/diagnosis/files/early-signs-of-dementia.pdf>

Alongside that is a video of a person talking about the impact of diagnosis: <http://www.scie.org.uk/socialcaretv/video-player.asp?v=gettingtoknowthepersonwithdementia>

The NES guide (pg 6-16) sets out the range of approaches to dementia: http://www.nes.scot.nhs.uk/media/351619/early_interventions_dementia_education_resource.pdf

SCIE have also provided a useful exercise to help you reflect on your learning about this: <http://www.scie.org.uk/publications/dementia/understanding-dementia/diagnosis/files/early-signs-of-dementia-activity.asp>

SCIE also have a good resource to enable you to think about preventative approaches: <http://www.scie.org.uk/publications/windowsofopportunity/interventions/prevention.asp>

Your focus should be on identifying what, if any, resources are appropriate to support the individual and their carer rather than formal care.

You should consider the least invasive solutions and encourage the person to identify what feels best for them. Bear in mind, social work involvement needs to be timely here, at a point where the person feels able to engage or when their carer expresses a need for help in their own right to carry on caring.

You should attempt a conversation with the person about how their daily functioning has changed at home and elsewhere. What ideas do they have about delaying this deterioration and how can they maintain their current lifestyle and identity simultaneously?

Remember that younger adults with a dementia diagnosis will likely face big challenges to do with obtaining or sustaining employment, parenting, and the still-present bias of dementia services being geared mainly towards catering for people in later stages of life. You will need to use your anti-discriminatory values and reflection skills to assist the person to overcome these hurdles.

Your role is in assisting the person to be making an active choice and plan as to how to remain independent and autonomous in the early stages of dementia. One aspect that many with dementia may require help with early on, is the setting up of plans to do with legal representation and finances (see unit on supporting carers).

When identifying the right early support through person-centred working, it is possible some needs will be harder to meet than others for a number of reasons. As a consequence of

⁵ NES (2009) An Educational Resource to Support Early Interventions for People receiving a Diagnosis of Dementia.

identifying resource gaps with the person, you should consider bringing any such deficit to the attention of the commissioning arm of your organisation. You could encourage the person/their carer to consider creating their own resource (see suggested resources in part 2, supporting carers).

Giving advice and guidance

Signposting and advising are crucial when supporting a person with dementia. There are multiple services, support networks and avenues of assistance for people in the early stages of dementia, but they are not always easy to navigate. You may want to read the guide by NHS Choices on activities to stay well <http://www.nhs.uk/Conditions/dementia-guide/Pages/dementia-activities.aspx> to inform your understanding of tasks and activities that are helpful for the person.

Your skills and abilities to be able to navigate a way through for the person and their carer are key. By using these, you will need to be able to identify the appropriate pathways and specialists (if the latter are required) for the person to contact. This aspect of social work brings in to play your ability to decipher referral systems, health and care terminology, and then translate the processes and meaning of all these back to the person (and their family, where appropriate).

You will need to work with the person to help them to a point where they have a level of acceptance around their condition or diagnosis. Encouraging them to see their GP could be part of this. There is a tension here as some might resist or deny their condition, difficulties, and have a right to do so. However, as a social worker, you might want to consider the sensitive task of explaining the Care Act [2014]'s new national eligibility criteria and what it means (including possible financial assistance towards help in the future as their condition advances).

You should try to help the person move beyond acceptance so they are in a place of control and able to forward-plan before their dementia is advanced to the point where they are no longer able to make informed decisions about their own care needs. This could include assisting them to plan a will, linking them in to research groups, supporting them to participate in service development, helping them write advance decisions around their care, or a do not resuscitate agreement. This might alleviate the commonly experienced sense of being 'a burden' by many with dementia. In a person-centred, empowered way, you need to help them forward plan to avoid further reliance and dependence further down the line.

Depending on your location you may find the Dementia Roadmap helpful which has been developed by the Royal College of GP's. <http://dementiaroadmap.info/> It is a web based platform that provides high quality information about the dementia journey alongside local information about services, support groups and care pathways to assist primary care staff to more effectively support people with dementia, their families and carers.

Multi-disciplinary working

The person with dementia is likely to need someone (a social worker usually, but not always) to co-ordinate teams, support, actions. This is about you liaising effectively with professionals in other disciplines as well as including the person and their carer/family. You need to take into account everyone in the person's network. So you need to feel confident and knowledgeable around when to delegate tasks out and to whom, be that the person, carer or another agency or service. This is a key social work role.

You need to manage and de-escalate anxieties held by others, both informal and formal members of the network. Your ability to do this lies in your evidence-based practice knowledge, and your decision-making ability.

This inter-professional work will probably revolve involve a thorough and robust risk assessment carried out by you in conjunction with at least one other professional. You will need to be able to reassure others and support them to avoid considering "knee-jerk" decisions on behalf of people with dementia such as unnecessary and damaging hospital admissions.

Don't underestimate how important your information sharing skills are with the person as well as others. You will need to be mindful of recording, information sharing, confidentiality, consent to share information from the person and the law around data protection.

You may need to involve particular disciplines such as a GP to conduct a medication review, community nurses to oversee nursing needs in the person's home, occupational therapists around carrying out functional tasks at home.

You should also have good knowledge of telecare to promote independence and wellbeing of the person in their own home. A pro-active multi-disciplinary team will be effective if it is communicating well and working together. The innate cohesion a social worker brings to this group is vital and your professional leadership and professionalism are needed for this.

Learning plan:

- Which of these practice areas do you feel confident in?
- Which areas do you need to improve through your own CPD and how will you do this?

Exercise/learning activity:

- How will you support and advise an adult/their carer in shock or denial about having dementia?
- What are the services/groups available locally for people in the early stages of dementia?
- How would you help an adult with dementia get a support group off the ground?
- In the future, what can you do to assert your professional view to prevent knee-jerk decisions by others which may be harmful for an adult with dementia?
- An adult in their 20s receives a dementia diagnosis and asks for help to retain their job. What sort of assistance would you give/be able to give?

5. Working with carers

The Care Act (2014) changes the legal status of carers immeasurably, placing them on the same footing as those who use services (service users) with the same entitlement to an assessment in their own right. Although separate carer assessments have existed for a while, this new legislation ensures that by law, a carer's assessment **MUST** be considered when assessing the cared-for person's needs.

The Carers Trust report on dementia *A Road Less Rocky* (2012)

https://professionals.carers.org/sites/default/files/dementia_report_road_less_rocky_final_low.pdf, provides a good starting point on setting out the issues that carers. As the report notes:

“The three critical points – diagnosis, taking on an ‘active’ caring role and the decline of the person with dementia’s capacity – which occur early in the caring journey, will arise for the majority of carers. They are extremely important opportunities for professionals and services to provide carers with initial information, advice and signposting.”

What we look at in this unit:

- Having the comprehensive knowledge and skills to undertake a carer's assessment.
- Your knowledge and confidence over carers' rights, both financial and legal.
- Assisting carers to assert own identity.
- How to help carers access or build their own resources.
- Ensuring preventative measures to minimise dependence on formal support.

Assessing a carer's needs

From a strengths-based perspective, there is plenty of evidence showing that great satisfaction can be achieved in a caring role for someone with dementia. However, carers **CAN** feel exhausted, trapped and require support for themselves in their own right. They often need a break, don't always actually want to be a carer, sometimes care out of a sense of duty, or experience levels of guilt and resentment about wanting more freedom.

Carers for those with dementia are likely to need support coming to terms with and handling loss. Specifically, loss of facets of the person they used to know, and a type of bereavement (often feelings that the person with dementia has 'gone' or 'isn't there anymore'.) You might need to consider how to help them reframe fears around death and dying.

It is crucial the carer's role gets recognition and there is acknowledgement of the value of the care they give and the love they may have and have shared with the person for many years.

The importance of the relationship they have with the person and the care they give is part of the cared-for person's world. Not only does the carer need to be supported in their own right, but they need to be included in any assessment or review for the cared-for person.

The carer will be coping with transitions of their own as well as for the person they care for. Carer inclusion will improve trust, avoid repetition, and should aim to reduce the carer's daily levels of strain and anxiety with the care they deliver. The carer's input into the assessment of the person with dementia should reduce the stress levels for both parties.

You will need to use negotiation, facilitation, empathy, active listening, paraphrasing, understanding and planning skills. This is not a process that can be rushed. You will need to appreciate the relational dynamic that can change between the person with dementia and their carer. This might involve occasional conflict or crisis for either or both parties. The carer's assessment will need contingency planning within it, co-authored between you. It should be a holistic picture of them as a person and a carer.

There are a number of sources of helpful advice for carers that you can signpost carers to. These include:

Carers-Looking After Yourself – audio and text:

http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=119

Carers speaking about respite care, dementia gateways:

<http://www.dudley.gov.uk/resident/care-health/dudley-social-services/do-you-need-support-now/social-care-services/dementia-gateways/>

Carers Trust. Alzheimer's And Dementia:

<http://www.carers.org/help-directory/alzheimers-and-dementia>

Ideas for carers to set up self-help groups or activities at home:

<http://www.mentalhealth.org.uk/content/assets/PDF/publications/dementia-self-help-guide.pdf?view=Standard>

A website for carers by carers:

www.dementiacarer.net

A carer's own identity

Often, carers have not ever considered themselves as being 'a carer' in the formal sense. Occasionally, some are uncomfortable with this label or actively dismiss it. Carers of those with dementia may minimise the strain they are under for a number reasons: guilt, pride, protection of the person they look after, fear that social services may see them as inadequate, or worse still, (especially with older people) that they may be 'put in a home'.

Social workers have the knowledge and skills to explore such issues, to allow the carer to share their views of what it means to them to be a carer. This may include helping them not to see the health deterioration of the adult they care for as their 'failure' (a common occurrence.)

Carers of dementia have reported feeling as though they lose their own identity behind their carer role. Some have said this feels like being a shadow. It is vital you provide carers the chance to discuss their emotions about where they want their life to go, what their hopes

are and how they might achieve them. By doing this, you offer a chance to build trust with the carer and should be helping them to manage realistic expectations of themselves and of you as the social worker. You should work alongside the carer to ensure, in line with Care Act (2014) Statutory Guidance, their opportunities to re-engage with training, education, paid employment and a social life of their own are maximised outside of their role of carer.

Carer networks and resources

You need to help reduce the carer's anxieties which might include helping them become more self-supporting through community links and networks (pre-existing or new.) It is important to retain a sense of where your own professional boundaries lie.

The concept of community capacity building (introduced by the personalisation agenda) suggests the enabling of carers (and others) to identify and make use of local resources. A useful source for carers is the Carers Trust search directory <http://www.carers.org/carers-services/find-your-local-service>. The Carers Trust are also encouraging the use of technology: <http://www.carersuk.org/help-and-advice/our-products-for-carers> and have specifically produced an app to support the care of a person with dementia. <https://www.jointlyapp.com/#welcome>

Carers of people with dementia need to build and maintain relationships. Social workers can assist by sign posting and identifying others who can support them. You do need to keep up to speed with the resources in your locality as much as possible. You should understand (referral) systems and be able to signpost at the right time. You need to know when to introduce a specialist service as well as and when something is not the domain of social work.

A systems or 'whole family' approach in your social working should be considered, helping the carer to consider what assets they have already, and what they need to identify. This is especially recommended if there are multiple (sometimes cross-generational) people with dementia in the household.

You should help the carer identify their own strengths in the present and for the future. You should be informed around accessible respite services to provide the carer a break from caring which feels right for them and those they care for. This will require you to support carers and families to reflect on their own needs, to reassure the carer, and assist them to complete contingency plans for if and when they are expectantly unable to care.

Basics like encouraging the carer to write lists are a good start; the pros and cons of caring. What works to keep them well, what makes them stressed and should be avoided. This is reliant on your partnership work with the carer.

The following graphic taken from work on resilience can be used as a visual to help individuals and carers identify the assets they have and can access.



Financial and legal rights for carers

Carers need to be informed around their financial and legal rights. This means you need to be able to discuss with confidence, their abilities to access direct payments to assist them in their caring role. Your legal and financial literacy and knowledge should be such that you are able to guide and advise the carer through the various systems in place. This does not mean you have to be an expert financial adviser, but you do need to know which teams and services can provide advice and guidance around income, benefits, and individual budgets.

Your ability to decipher information and translate terminology will come in to play and you need to help carers feel less frightened in this area of finance and law. You should be able to direct them to debt management help, legal representation, assist them to appeal funding outcomes (both from social care and health agencies), and be able to de-escalate any anxiety or confusion they may have about the definition, function and responsibilities of being a person's Lasting Power Of Attorney.

The Department of Health have set out guides for carers:

Care and Support: What's Changing:

<https://www.gov.uk/government/publications/care-and-support-whats-changing/care-and-support-whats-changing#support-for-carers>

You can find the statutory guidance for professionals operating under the Care Act (2014):

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/366104/43380_23902777_Care_Act_Book.pdf

Carers benefits information:

<https://www.gov.uk/browse/benefits/disability>

Learning plan:

- Which of these practice areas do you feel confident in?
- Which areas do you need to improve through your own CPD and how will you do this?

Exercise/learning activity:

- Look at the Care Act (2014)'s chapter on carers in a discussion with colleagues. Re-group to test each other on the changes this new law brings for carers.
- Think about how new legal carers' rights might impact a carer of someone with dementia.
- Consider conversations with the person around how they think their carer is managing.
- Are you familiar with local groups offering grief and loss support or counselling? For example, 'Cruise'?
- Is there a 'Death Café' nearby? Do you know what they are? Would it help the carer? (See resource below.)
- Use genograms or mind-maps with carers of those with dementia to remind them of their networks and where they might strengthen them.

6. Advocating and challenging

The person's right to take part in discussion and planning (even in a quasi-manner) is now enshrined in law (Care Act 2014) and so, advocacy for them as well as necessary challenging on their behalf now plays an even bigger role in your social work practice for and with adults who have dementia (and their carers).

Part of representing a person with dementia well is ensuring their thoughts and views are heard if they can not give them themselves. Either you need to feel confident enough to do this or be able to delegate to another to do so, giving them the appropriate level of information required. The Care Act (2014) has introduced a new duty to ensure that where an adult may be unable to fully participate in any assessment or review of their own needs, that they are offered access to an advocate in such circumstances.

Your professional values alongside the legal requirements require you to work in ways which advocate for the person and challenge attitudinal/system barriers to their voices being heard and needs being supported.

What we look at in this unit:

- The need to challenging stigma, assumptions, uninformed decisions and poor knowledge.
- Showing leadership, knowledge and direction in a multi-disciplinary environment.
- Challenging poor systems and services.
- Being able to contribute towards re-shaping and improving support and services.
- Boundaries: Knowing your role and involvement.
- Ensuring your own legal literacy and confidence in advocating.

Understanding systems

Navigating through the systems, referral pathways and services will be a key aspect of your advocacy for a person with dementia. You will have to be able to de-code professional terminology on their behalf and then relay the meaning of it, as much as possible, back to the person and or their carer.

With a view to ending your involvement safely and in a timely way, you will need to put into place what the person needs to become as self-sufficient as possible. You should think about how you explain this to the person and be mindful of your own language, bias and value base. Be honest with yourself and with the person you are representing.

You will need to remember that someone with dementia may have difficulty remembering issues in the long term as well as the day to day. Consider what they need to know and what you can leave out. You may want to plan how simple information is delivered as effectively as possible towards their loved-ones and support network.

You should draw on your knowledge of local resources including medical models of help. You need to understand the financial implications of any decisions you have to make on the person's behalf. Ensure you understand and are conversant with national and localised procedures and policies and that you also understand what is available from secondary providers and the voluntary sector.

Challenging on behalf of the person

Social workers need to challenge poor decisions or discriminatory practice that affects a person with dementia negatively. You should feel confident in your ability to manage conflict and come to a satisfactory resolution with carers, friends, family or other professionals. Be confident in your knowledge of the principles contained within the Human Rights Act (1998) and the Equality Act (2010).

If you are taking decisions via the Mental Capacity Act (2005) assessment route ([Best Interest decisions – see Department of Health curriculum guide on the Mental Capacity Act 2005](#)) you must ensure that decisions are proportionate and are the least restrictive option for the person ([in line with the MCA code of practice](#)) http://www.legislation.gov.uk/ukpga/2005/9/pdfs/ukpgacop_20050009_en.pdf. You may have to challenge the person themselves and or their carer/family or indeed other professionals if, for example, the person's inability to make capacitated decisions as assessed by you leaves them (or a third party) at high risk of significant harm.

A person with (advanced) dementia may be at more risk of requiring help within a safeguarding scenario (especially when, for example, they may be declining support which assists them to remain safe). In this situation, more than ever, your advocacy on their behalf must be evidence-based, with their best interests at the centre of your work. You should familiarise yourself with the new duties introduced by the Care Act (2014), placing safeguarding on a statutory footing for the first time (in conjunction with your organisation's own internal procedures that run alongside the new law).

While challenging on the person's behalf, bear in mind part of what you are doing is adhering to the Care Act (2014)'s central philosophy of keeping the person at the centre of your practice. Working in this way you must do everything to avoid the 'pass the parcel' syndrome which occurs between teams that communicate poorly with each other.

You need to challenge shifting referral systems and insist the person comes before any service-lead practice from elsewhere, while maintaining a constructive, diplomatic stance throughout. Don't forget some of the challenging expected of you will also be about service standards, and you need to be able to produce an evidence-based argument regarding such scenarios that remains factual and practical and that does not compromise future and necessary professional relationships.

People with dementia are at risk of not always being able to fully understand the assessment or review process – this brings into the play the new legal duty via the Care Act (2014) to ensure their right to access an advocate for this purpose. In conjunction with this, remember that explaining any such right to the person or their carer will also need to be delivered in a jargon-free way. These skills all aim towards ensuring the person has access to the right support at the right time for them.

Stigma and addressing discrimination:

There will be many with dementia who are still active and involved in their communities, but will be perceived as being unable to speak for themselves. The Age Concern Advocacy Project report *Someone to Speak up for Me 2009* highlighted this well.

http://www.ageuk.org.uk/documents/en-gb/for-professionals/health-and-wellbeing/139_0809_someone_to_speak_up_for_me_2009_pro.pdf?dtrk=true

Older people who lack mental capacity for some decisions have little or no voice and are among the most excluded groups in society today. Developments in technology increasingly allow us to explore innovative ways to enable these voices to be heard.

'Lacking mental capacity' is a label that many people cannot see beyond, but in spite of it many older people are able to express their views, wishes and choices, given the opportunity and the right support.

Anxiety and aggression and other 'challenging behaviours' in older people are often wrongly ascribed to a mental illness rather than to potentially treatable causes such as infection control and pain management.

Problems and crises in the lives of older people do not fall into neat, service-defined pigeonholes. A holistic approach is needed that rebuilds the often lost community connections with the older person.

Addressing the stigma attached to someone's inability to self-advocate is central to you representing them in a way that is ethical and person-centred. Social workers must retain their strengths-based working methods in this and ensure periods of reflection upon their own practice to stay mindful of why they are doing what they are doing and how they are doing it. This includes you needing to acknowledge ability beyond disability throughout your advocacy, however difficult it is to interpret a person's wishes.

Adults with dementia and a learning disability will have, or be, facing additional layers of stigma (lifelong) and discrimination. This is a growing group of adults with whom you will come in to contact. You need to grant yourself the professional investment time to read about how best this group can be represented by social workers in a meaningful, person-centred way. Get involved and become curious about working groups regarding the change in our adult demographics (see resource below on learning disability and dementia).

<http://www.macintyrecharity.org/wp-content/uploads/2014/11/Hot-Tips-for-Supporting-People.pdf>

Inter-professional, multi-disciplinary role and professionalism

There are a variety of challenges when working with other disciplines in the person's network. Your training will have been steeped in the 'social model', but you need to understand the nuances of the 'medical model' and its history, values, current place in context. There are obvious but also subtle differences between the two. You should familiarise yourself with medical language. You need to remain conscious of the power ratios between medical and social care professions, and associated interactions. You will need to be good at using the language other professions listen to – harnessing its power and using your own professional style to obtain the input of others.

Your professional leadership skills will be called upon so that, you can put into practice your authority in a proportionate and measured manner. A degree of negotiation is required of you as you will need to overcome varying elements of resistance. You may need to remind non-social worker colleagues that adults with dementia still have agency, determination, and a need for control in their lives and care planning decisions. You may need to manage the anxieties of other professionals when collective decisions on the behalf of the adult with dementia need to be taken.

Be prepared to challenge knee-jerk, risk averse tendencies, for example, not thinking the person with dementia can have a sex life, drink alcohol, as they always might have done through life. Another example might be about carers or professionals wanting to admit the person into residential care. You will need to ensure the adult's rights to privacy, autonomy and power are wholeheartedly considered in any such discussion/decision making.

Representing the person, Mental Capacity Act (2005)

Because you will have interactions with the person, carers, relatives, friends and other professionals you will need to use differing styles of communication, depending on the audience. Your self-confidence to use your authority in a legal, person-centred, sensitive manner will be imperative. You need to strike a balance with the person, their informal network, and professionals, to be able to follow legal pathways and procedures if they are necessary, and be able to explain why.

Our [curriculum guide on social work with the MCA \(2005\)](#) explains in more detail that essentially, you need to be able to complete an MCA assessment, explain how it works, what it is for, why it is required, talk through your findings, and reassure others what the next steps are. You must be able to discuss the least restrictive options with the person (and others involved). Through this process, you are expected to educate others in this area of the law, explicitly or implicitly. Conducting forums in which to make Best Interests decisions will be another area where your capability and legal literacy will be key.

It won't always be you who needs to be the person's representative. It's as important you know when to represent as when not to. So knowing the law regarding advocacy as dictated by the Care Act (2014), through to understanding the necessary criteria attached to involving an Independent Mental Capacity Advocate (IMCA) should be at the centre of your advocacy.

Learning plan:

- Which of these practice areas do you feel confident in?
- Which areas do you need to improve through your own CPD and how will you do this?

Exercise/learning activity:

- Are there local advocacy research projects you can become involved in as part of your work?
- Could you start one as part of your continued professional development?
- Which types of support are hard to access for a person with dementia? How can you tackle this differently?
- How will you challenge decisions made by those in more traditionally authoritative roles (consultants, psychiatrists for example) when the person's rights might be contravened?
- Suggest a monthly group supervision to look at advocacy issues to learn how colleagues have represented people with dementia: What worked? What didn't work?

7. Triangulation

“The Triangle of Care for Dementia describes how meaningful involvement and inclusion of carers can lead to better care for people with dementia. In an ideal situation the needs of the carer and the person with dementia are both met. Inclusion of people with dementia and support in making decisions is therefore fundamental to its success. This will then complete the triangle” (Carers Trust. The Triangle Of Care):

<http://static.carers.org/files/the-triangle-of-care-carers-included-best-practice-in-dementia-care-final-6870.pdf>

Social workers at our practice workshops emphasised how crucial it is to have the essential skills of triangulation. In essence this is about being able to build and maintain relationships, to gather information from a third party (usually the main informal carer), and to use that to make decisions that are robust and defensible. This very much adheres to the partnership working theme of the Care Act (2014) and marries communicative skills with the ability to gather information in a focussed, efficient, analytic and dynamic way.

Other units have already skills in relationship building and working with and supporting carers. This focuses on how you work with all those involved in the interest of supporting the person with dementia.

What we look at in this unit:

- Your ability to judge the quality and content of information within the context of your work.
- Remaining open-minded about the source of information and any attached agendas.
- Ensuring your information gathering practice uses third party validation.
- Being able to identify delegation opportunities that will achieve the best outcome.

Multi-disciplinary team working

When working with a person who has dementia, you will invariably become involved as part of or be the key professional within, a multi-disciplinary team (MDT). This will require you to be aware of your professional duties and boundaries, but assert yourself professionally. You should bear in mind the social work ‘drawbridge’ concept, in other words – knowing where your duty of care starts and ends.

It is also using the skills of diplomacy and liaison i.e. negotiation, co-ordination, and collaboration. Consider what style of communication you might use to go about managing other professionals’ and the range of knowledge each will have of dementia and its impact.

You need to ensure consistency and continuity throughout any contact with the person or their representatives. You need to balance information collection and recording with multiple individuals, sometimes in person and together, for example, when you visit the person jointly with other professionals. You need to know when you are the person to ask the questions and when you aren't. You should be realistic about what is achievable in terms of how much information you can gather and use. There is a danger that you can get into gathering lots of information but fail to be curious in considering its relevance and meaning in the context of this person.

Information gathering requires you to take a holistic approach and make the most of the 'triangle of care', ie you, the person and their main informal carer. Within this, you should consider how you ensure you remain open-minded and appreciate EVERYONE'S agenda. Social workers have to be conscious of the differing contexts and agendas at play, and must remain open-minded and non-judgemental whilst applying critical analysis to the information. This does not mean disbelieving others, but you should reflect on the who/why/when/what of all sources of information.

Where to assess and with whom to consult

Social workers have told us that triangulation methods can be used to determine where best to work with, assess and review a person's needs when their dementia prevents them from having the ability to fully participate in this process. Gathering a person's history when they are unable to give it themselves is central to supporting the person.

To do so you need to gain observations from as many people involved as possible, in order to develop the richest and most robust picture of the person which encompasses a sense of who they are not and not just their perceived care needs. Your professional leadership abilities are key in this and you must be able to determine who the right people and information givers are, while identifying and overcoming any conflictual agendas.

You can consider exercises with the carer/network such as 'gap analysis' which can help identify what's needed if missing and what can be achieved in reality and ecomaps which can help identify networks, sources of support/concern. Think about avoiding service-led scenarios that can creep into practice and discriminate against a person with dementia covertly.

Knowledge of resources, confidence to advise

The person with dementia and their carers will be looking to you and others in the MDT to provide a response which is personalised and informed. You should be able to suggest strategies and skills the carer might try to meet the needs of the person more effectively with the support of other professionals. There is an expectation that you will have a comprehensive knowledge of local dementia-friendly resources. Reassuring the carer of a local facility's function, and how it might meet the needs of the person, will assist you in strengthening the triangulation required for information gathering at a stage where the person's dementia is advancing.

Change is a frequent factor and your ability to introduce, nurture and manage change safely will be called upon. Positive reinforcement may help with this, as well as frequent discussions and the confidence to slow things down. Social workers have shared that a professional assertion to improve the outcome is vital, for example, to ensure someone is discharged from hospital safely, avoiding unnecessary and dangerous readmissions.

It is important you feel able to represent a Multi-Disciplinary Team (MDT) and deliver its joint views and recommendations. You should consider how you will ensure these recommendations remain owned collectively by the MDT, with you (in some instances) being the leader and holding true to what's agreed as right for the person.

Achieving the right outcome for the person via triangulation should involve regular discussions with senior colleagues for your own direction. Remember to request and instigate regular reflective time for your practice throughout the triangulation and MDT working. You should think ahead – what discussion is needed with managers to secure funding for what may lie ahead for the person?

Evidence-based, defensible decisions:

Social work practice with adults who have dementia must be evidenced based and defensible, not decision making based on defensive practice. This relies upon the decisions you take being shared and owned (when necessary) with others. You need to be clear about what and who you are accountable to and be able demonstrate what informed your decision making.

You will be adhering to the [MCA code of practice](#) (Unless the MCA assessment shows incapacity) and seeking third party views. Any decision made must be in the person's best interests in the wider sense (if made outside the context of the Mental Capacity Act). It's important the person's wishes and choices made both before and since their diagnosis are considered. Has their behaviour changed and what was learnt previously with regard to best outcomes for the person?

When working via the person's main informal carer, you should use their information towards robust planning, assessing and managing. You will need to consider how you use the views of colleagues to assist in your information analysis. This provides more reliable evidence beyond any linear views shared which may give cause for concern, for example, if a carer is withholding information for some reason.

On occasion a carer may struggling to explain their loved-one's views/needs, with the more complex aspects, a third party view cements your practice in an accountable way. You need to feel confident to approach a colleague when unpicking information. You might need to reflect with other professionals on the validity of information shared, while focussing on the wider context.

Fact-finding is often the bread and butter of social work but there may be times where, for efficiency's sake, you may have to consider requesting other professionals to gather information from the carer or others. This means building and maintaining your delegation skills with colleagues in other agencies. You should think about proportionate and appropriate checks and balances to verify information and be aware of all agendas at play – from any family dynamics to funding restrictions.

Ethics of person-centred MDT work:

Triangulation should follow the principles seen in the MCA Code of Practice (see [Department of Health Curriculum guide on the Mental Capacity Act \[2005\]](#).) In short, any decision you make should be in the person's best interests and be proportionate to the needs and possible risks being assessed. A partnership-approach lends itself to this way of working.

Retaining the person's views is paramount. You need to work towards assurance from others to respect the individual's integrity while sharing and discussing information about them subject to legal and professional boundaries. Consistency is crucial in how you work with colleagues and with the contact you have with the person and their carer(s).

There is a fine balance to be achieved when it comes to sharing information across the MDT. You need to be willing to share what is necessary as do your colleagues in a manner that is proportionate. Of course, you also need to feel confident in your knowledge around confidentiality.

Remember to be conversant with the [Human Rights Act \(1998\)](#) and feel able to explain the person's rights using this legislation. Can you explain to all parties the research showing evidence of how different factors can mitigate risk, risk aversion versus risk enablement, and a person's right to make an unwise decision (MCA [2005])?

Better outcomes and interpreting the person's behaviour takes time:

According to the social workers we consulted, adults with dementia can sometimes show behaviour that's very difficult to interpret, or that may be easy to misinterpret. Often someone's history (employment, life events and so on) holds the clues. You need to protect and guard your professional space and time to explore this via the person and their carer. (You may want to read the blog <http://dementiaproject.net/blog/?p=189>) Working with the carer to build, for example, a personal profile or life journal might help. You should feel comfortable trying different methods of person-centred information gathering such as these. In order to 'get it right', and avoid knee-jerk decisions or misplaced actions, you must pay attention to details.

The cartoon book by Tony Husband:

http://www.dailymail.co.uk/health/article-2623800/The-saddest-goodbye-Endless-words-written-dementia-But-ANY-match-poignancy-cartoonist-Tony-Husbands-account-watching-steal-away-father.html?ITO=1490&ns_mchannel=rss&ns_campaign=1490

does capture this well.

Listen to past experiences from the person and their carer/family. Think how to involve the person's carer/family, helping them move from negative into positive experiences of how social work can enable. Observe and reflect upon any family dynamics.

You might need to identify another professional with whom the person feels safest and connects. Make the most of this connection. Your ability to delegate to, support and co-ordinate with other colleagues is what might allow the use of this dynamic to monitor and review outside of traditional social work parameters.

Learning plan:

- Which of these practice areas do you feel confident in?
- Which areas do you need to improve through your own CPD and how will you do this?

Exercise/learning activity:

- How will you work **ALONGSIDE** a carer, as opposed to with a carer in your next piece of work?
- How confident are you knowing the tipping point between sharing information and having to discuss with senior colleagues to assess levels of risk?
- How familiar are you with the MCA Code of Practice? Can you access e-learning on this to bring your knowledge up to speed?
- Write a life journal for yourself or agree to do this with a colleague. Re-group to discuss how this made you feel, what you considered in relation to lifetime achievements, ambitions, and priorities.

8. Other core practice areas

In addition to the 6 main units covered within this manual, social workers (as well as adults using services and carers) attending our workshops who provided their views on what good practice looked like also mentioned these areas to consider:

- Being able to have varied communication and interview skills to fit different audiences (people who have dementia, carers, other professionals, housing personnel, legal staff, senior managers).
- Having faith in your own practice skills, confidence to stop, reflect, and re-examine your decisions.
- Ability to be a good observer, monitor, measurer and a background observer.
- Confidence to try differing assessment styles, eg occupational therapy-style functional assessments ('tell me' questioning techniques).
- Autonomy to be creative in co-production of support, try new ways.
- Awareness of dementia-related sequencing difficulties, the need to break down tasks.
- Ability to manage the tension between time and targets.
- Group supervision, knowledge share for practice regarding adults with dementia.

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9. Additional dementia resources

Theme	Topic	Link
Policy	National Dementia Declaration for England	http://www.dementiaaction.org.uk/assets/0000/1157/National_Dementia_Declaration_for_England.pdf
	The Real Dementia Challenge	http://www.ageuk.org.uk/Documents/EN-GB/For-professionals/Research/Mike%20Fisher%20presentation.pdf?dtrk=true
	Prime Minister's Challenge on Dementia 2020	https://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020
Learning	SCIE e-Learning. The Open Dementia programme:	http://www.scie.org.uk/publications/elearning/dementia/index.asp
	SCIE open dementia programme – Films and e-learning for Carers:	http://www.scie.org.uk/assets/elearning/dementia/dementia02/resource/flash/index.html
	SCIE dementia care website:	http://www.scie.org.uk/key-topics/dementia-care
	SCIE. Working In Partnership with Carers:	http://www.scie.org.uk/publications/dementia/living-with-dementia/working-with-carers/files/working-alongside-carers.pdf
	SCIE. Dementia Risk Factors:	You will need to set up an account with SCIE http://www.scie.org.uk/publications/dementia/understanding-dementia/diagnosis/files/dementia-risk-factors.pdf
	e-learning for Healthcare	http://www.e-lfh.org.uk/programmes/dementia/open-access-sessions/

Theme	Topic	Link
	FAMILY PERSPECTIVE:	http://www.dailymail.co.uk/health/article-2623800/The-saddest-goodbye-Endless-words-written-dementia-But-ANY-match-poignancy-cartoonist-Tony-Husbands-account-watching-steal-away-father.html?ITO=1490&ns_mchannel=rss&ns_campaign=1490
	House Of Memories:	http://www.liverpoolmuseums.org.uk/learning/projects/house-of-memories/index.aspx
	Art therapy for those with dementia and their carers	http://www.engageandcreate.com/ignite-sessions.html
Activities	Lifestory and reminiscence work	http://www.iriss.org.uk/resources/supporting-those-dementia-reminiscence-therapy-and-life-story-work
	Music And Memory iPod Project	https://www.youtube.com/watch?v=EgNLLelQYwI
	Activities for dementia	http://www.macintyrecharity.org/wp-content/uploads/2014/11/Hot-Tips-for-Activities.pdf
	Playlist for Life (Ways To Connect Those With Dementia and Their Carers Through Music):	http://www.playlistforlife.org.uk/
	Music And Memory Current Research Listings	http://musicandmemory.org/music-brain-resources/current-research/
	Sporting Memories	http://sportingmemoriesnetwork.com/projects/setting-up-a-sports-reminiscence-project-or-group/
	Enabling People with Dementia To Enjoy The Outdoors	http://dementiaadventure.co.uk/
	Arts4Dementia	http://www.arts4dementia.org.uk/
	Alzheimer's Society – Visitor's Book	http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=2346
Bloggers	Beth Britton	http://www.bethbritton.com/index.htm

Theme	Topic	Link
	Norman Macnamara	Norman Macnamara: I Have Dementia, Deal With It https://www.youtube.com/watch?v=wvrgcB_JFGI&feature=youtu.be
Diversity	SEXUALITY/LGBT	http://www.nationalcareforum.org.uk/viewNews.asp?news_ID=2511&sector_id
		http://www.alzheimers.org.uk/site/scripts/documents.php?categoryID=200369
		http://www.thelabrystrust.com/uploads/1/1/7/4/11743016/labrys_trust_research_report_march_2013_v3_for_pdf-1.pdf
	Information for LGBT people, their friends, partners and family:	http://www.dementiaaction.org.uk/assets/0001/1068/Dementia_doesn_t_discriminate_LGBT_leaflet.pdf
	BME	Findings from one day learning event http://www.raceequalityfoundation.org.uk/resources/downloads/dementia-black-and-minority-ethnic-communities http://www.raceequalityfoundation.org.uk/dh-strategic-partners/dementia/events
		Briefing paper http://www.better-health.org.uk/briefings/black-and-minority-ethnic-communities-and-dementia-where-are-we-now
		http://www.scie.org.uk/publications/briefings/briefing35/
	People With Learning Disabilities	http://www.learningdisabilities.org.uk/help-information/learning-disability-a-z/d/dementia/
Specific issues	Managing Behaviours	https://fightdementia.org.au/support-and-services/families-and-friends/coping-with-behaviour-changes/wandering#Reasons%20for%20wandering
	Personalisation and Dementia. A Practitioner's Guide	http://www.mentalhealth.org.uk/content/assets/PDF/publications/Dementia-Choices-Guide.pdf?view=Standard
	Sex	http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=129

Theme	Topic	Link
		http://www.scie.org.uk/publications/dementia/living-with-dementia/difficult-situations/files/sexual-expression.pdf?res=true
	advocacy	MIND - Finding The Right Advocate: http://www.mind.org.uk/information-support/guides-to-support-and-services/advocacy-in-mental-health/finding-an-advocate/#.VP785csfyUk
		Independent Mental Capacity Advocacy (SCIE TV Film): http://www.dudleyadvocacy.org/#!imca/cpxs
		Dementia Action Alliance – Examples of Regional Advocacy Services: http://www.dementiaaction.org.uk/search?q=advocacy
Online forums	Alzheimer’s Society	http://forum.alzheimers.org.uk/forum.php
Dementia friendly communities	Alzheimers society	http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=1843
	The Purple Angel	http://www.purpleangel-global.com/understanding.html
	Dementia Friends	https://www.dementiafriends.org.uk/
	SCIE: Ways to build social capital:	http://www.scie.org.uk/publications/windowsofopportunity/interventions/buildingsocialcapitalstudies.asp
Services	Admiral Nursing information	http://www.dementiauk.org/what-we-do/admiral-nurses/
		http://www.britishlegion.org.uk/can-we-help/care-and-support/dementia-care/admiral-nurses-dementia-care
	Dementia Roadmap	http://dementiaroadmap.info/

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