Dementia in the Workplace
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1. Introduction

At RCN Congress 2017, the following resolution was passed:

This meeting of Congress urges RCN Council to develop a strategy for supporting members with dementia to continue nursing.

In response to this resolution, a suite of information aimed at nursing staff and those that represent and employ them has been developed. The aim of this suite is to tackle the stigma surrounding a diagnosis of dementia in working life and to support nurses with dementia to work as fully as they are able to, for as long as they wish to.

The information suite contains the following:

- position statement
- information about the Dementia Friends scheme
- brief guide to dementia in the working age population
- information for nurses and HCAs worried about dementia
- information for representatives supporting a member who has or may have dementia
- information for line managers who are worried that a member of their team may have dementia.

This information may be of interest to those caring for someone with dementia, but it is not intended to be a guide on carers’ rights. Such information can be found at [www.carersuk.org](http://www.carersuk.org) (accessed 24/8/18)
2. Position statement

A dementia diagnosis should not automatically equal unemployment. Our country has to adapt to its ageing population and so must employers adapt to an ageing workforce; by ruling out people diagnosed with dementia, employers are potentially ruling out capable workers.

Dementia needs to be treated in the same way as any other disability. Nursing staff need to be open and honest about their physical and mental health while employers, in turn, should adapt their working arrangements accordingly. Support before and during diagnosis is key to ensuring that staff feel supported and able to have transparent conversations at every stage of their journey. Such open and honest dialogue is necessary to manage potential risk.

The RCN can support both nursing staff and their managers to have the right conversations and make the adjustments necessary to suit all those involved. We will work to eradicate the stigma surrounding dementia in the workplace so that there can be open discussion about when nurses and HCAs are still able to work and when it is time to move on.

3. Dementia Friends

The RCN encourages all its staff, representatives and members to become Dementia Friends.

“Being a Dementia Friend simply means learning more about dementia, putting yourself in the shoes of someone living with the condition, and turning your understanding into action. From visiting someone you know with dementia to being more patient in a shop queue, every action counts.”

(Alzheimer’s Society, 2017a)

The Dementia Friends campaign aims to increase public awareness of the challenges that people with dementia encounter in everyday life. Not only will this enhance your clinical training and practice, but if you are representing someone who may have or has already been diagnosed with dementia, it will give you valuable insight that will help your work with them.

Find out how to become a Dementia Friend here: www.dementiafriends.org.uk (accessed 24/8/18)
4. Brief guide to dementia in the working age population

Dementia is caused by a number of diseases that affect the brain.

The most common is Alzheimer’s, but diseases also include vascular dementia, dementia with Lewy bodies and Pick’s disease.

The Alzheimer’s Society states that:

*The word ‘dementia’ describes a set of symptoms that may include memory loss and difficulties with thinking, problem-solving or language. These changes are often small to start with, but for someone with dementia they have become severe enough to affect daily life. A person with dementia may also experience changes in their mood or behaviour.*  
(Alzheimer’s Society, 2017b)

A spectrum disorder, dementia progresses in a way that is unique to each individual. Someone’s personal circumstances, the people around them and the environment in which they live will also affect their experience of dementia.

This guide does not cover issues relating to the care of patients and service users with dementia. However, in its role of shaping, developing and promoting excellent nursing practice, the RCN has developed a resource for clinical practice in dementia: [www.rcn.org.uk/clinical-topics/dementia](http://www.rcn.org.uk/clinical-topics/dementia) (accessed 24/8/18).

Of particular note are the SPACE principles of dementia care – which can also be translated into workplace support *(suggestions in italics).*

**SPACE principles of good dementia care**

- **Staff who are skilled and have time to care** (managers and reps who have a good understanding of dementia and commit the time to support their colleagues living with the condition).

- **Partnership working with carers** (managers and reps working in partnership with staff living with the condition and their carers if appropriate).

- **Assessment and early identification of people living with dementia** (early intervention at work, looking at job adaptations and reasonable adjustments in a timely manner, not only when difficulties arise).

- **Care plans that are person-centred and individualised** (employment support that is person-centred and individualised).

- **Environments that are dementia-friendly** (working environments that are dementia-friendly).
According to Age UK, the following are typical early indicators of a possible dementia diagnosis:

- Struggling to remember things that happened recently, even though you can easily remember things from longer ago.
- Struggling to follow conversations, particularly in groups.
- Forgetting the names of people or things.
- Struggling to follow a story on television or in a book, or understand magazine and newspaper articles.
- Having trouble remembering the day or date.
- Having trouble remembering where you put something, or where things are kept.
- Repeating yourself or losing the thread of what you are saying.
- Finding your thinking is fuzzy.
- Struggling to do things you used to find easy.
- Feeling confused, even in a familiar place.
- Having problems controlling your mood, or controlling your emotions.

(Age UK, 2017)

However, despite common thinking, dementia is not exclusively an older person’s disease. In 2015 the Alzheimer’s Society found that over 40,000 people under the age of 65 had been diagnosed with dementia but that only 18% continued to work after diagnosis (Alzheimer’s Society, 2015).

There are a number of reasons why this may be, including:

- diagnosis can take a long time, and by the time it is confirmed a person has had to leave work.
- people prefer to leave work to spend time with family and friends and pursue other interests while they can enjoy them fully.

However, in many cases employers just do not know how best to support their staff. An Acas survey found that 9 out of 10 employers recognised that dementia was a growing issue for their organisation and their staff and a Centre for Economics and Business Research survey found that 1 in 10 were already employing someone with the condition (Alzheimer’s Society, 2015).

Young Dementia UK was set up to support the growing number of people diagnosed with dementia at an early age (before age 65). www.youngdementiauk.org (accessed 24/8/18)

The Alzheimer’s Society encourages employers to become “dementia friendly” and lists the following as reasons why:

- It’s the right thing to do.
- It will help retain staff.
- It will help the organisation become an employer of choice.
- The organisation will provide a more inclusive service.
- It will future-proof the organisation.
- It will contribute to increased productivity.
- The organisation will be fulfilling its legal responsibilities.

(Alzheimer’s Society, 2015)

Full information on becoming a dementia friendly workplace can be found here: www.alzheimers.org.uk/info/20116/making_organisations_more_dementia-friendly/357/creating_a_dementia_friendly_workplace (accessed 24/8/18)

The RCN believes that, with the right support and reasonable adjustments, nurses with a diagnosis of dementia may still be able to contribute to excellent patient care and that a diagnosis alone should not automatically lead to their exit from the workforce.
5. Information for nurses

As nurses and care practitioners you will no doubt have come into contact with patients, clients or carers affected by dementia. But what if you are concerned about your own wellbeing? What should you do?

If you have started having problems remembering things that have happened recently, are feeling confused or are finding that your thinking is “fuzzy”, you may be worried that these are early signs of dementia. Feelings of anxiety and apprehension are to be expected, but fear of the unknown is often worse than the truth.

However, do remember that being forgetful or getting confused doesn’t necessarily mean you have dementia. Dementia-like symptoms can be caused by depression, vitamin deficiencies, stress, thyroid problems or urinary tract infections.

But if you’re worried, it’s always best to talk to your doctor as soon as possible to discover what’s causing the problems.

Your doctor will:

• discuss your concerns and symptoms
• ask questions to test your thinking and memory
• carry out a full health check to see whether your symptoms could be due to other causes
• if necessary, refer you to a specialist or a memory clinic for a fuller assessment.

You may wish to take a relative or friend with you to the appointment, as it can be hard to take in everything that you are being told if you are stressed and worried.

Age UK (2017) states that:

*Getting a diagnosis [of early-stage dementia] won’t make things worse, but it can help you make changes to live as well as possible and make plans for the future.*

If you are on the NMC register you have a responsibility under the NMC Code of Conduct to “prioritise people, practise effectively, preserve safety and promote professionalism and trust” (NMC, 2015). This includes taking responsibility for your own health and wellbeing and recognising if it is having a negative impact on your ability to perform your nursing duties safely and effectively.

For example, look at the following two areas of the Code of Conduct:

16) Act without delay if you believe that there is a risk to patient safety or public protection – are you aware that you are in danger of making mistakes at work?

19) Be aware of, and reduce as far as possible, any potential for harm associated with your practice – are the symptoms you are experiencing affecting your practice?

Although it will be difficult, you should try to talk to your line manager about your fears and what you are doing about them at the earliest opportunity.

Your manager may ask you to seek advice and support from Occupational Health and may want to restrict your duties or ask you to take a period of medical leave (which should be on full pay) while you do so and until you receive a diagnosis.
Case study – the nurse’s tale

My name is Jaine and I qualified as a nurse in 1983. I’m 57 years old.

A few months ago my partner commented on how forgetful I had become and how I often appeared to be “vacant” and confused. I must confess I’d worried about this myself but put it down to my age and the stress I’ve felt under at work, plus my hormones. My experience of the menopause hadn’t been a great one – it knocked me off my game at times. No one had said anything at work but I had a feeling colleagues were avoiding me or not asking me to do things they otherwise would have done.

One day my friend at work sat me down to tell me how worried he was about me, that I wasn’t quite myself. I have to say I was really relieved to be able to talk openly to him about how worried I was too. Two of my older relatives had dementia and I’d nursed many older patients with the condition myself. Actually saying the words out loud that I was worried I was in the early stages was so hard, but so important.

My colleague was great, really supportive and had already looked into what to do if this was a possibility. He encouraged me to talk to my GP first but also reminded me of my professional responsibilities and suggested I confide in our line manager too. That felt very scary but I knew he was right. I decided to do some investigating myself before I did so and steeled myself to make an appointment with my GP as soon as I could. I looked online for resources that might help.

My GP was understanding if a bit rushed, but thankfully took me seriously and referred me to the neurologist. Dementia was only one of a number of possible things that needed checking out. I spoke to my line manager and arranged some time off on paid sick leave. I’d made it clear I wasn’t giving up or giving in but I needed a bit of space to sort things out – whichever way things turned out. My employer offers a counselling service too, and although I was initially hesitant to use them in case they “reported” me, I’m glad I decided to speak to them as I could talk to them about things I didn’t want to worry my partner with.

When my diagnosis was confirmed I felt sick and scared. I knew the long-term prognosis but also knew that I was still capable of so much. Being supported to continue in work and to keep nursing was really important for me and my sense of worth and self-esteem. The RCN’s suite of information about dementia care was really useful too, for me and my partner.
Your employer has certain obligations towards you. As well as a general duty of care, they must also comply with the requirements of the Equality Act 2010 (Disability Discrimination Act in Northern Ireland), which state that they must not discriminate against you (directly or indirectly) on account of a disability or perceived disability and they must make reasonable adjustments to your employment if they would allow you to continue working. For more information about reasonable adjustments see information provided by the RCN’s Peer Support service: [www.rcn.org.uk/peersupport](http://www.rcn.org.uk/peersupport) (accessed 24/8/18)

It’s better to raise the matter yourself than face complaints or allegations of being unfit to practise.

The NMC states:

*We will not normally need to intervene in a nurse or midwife’s practice due to ill health unless there is a risk of harm to patients and a related risk to public confidence in the profession.*

(NMC, 2017)

Work with your employer to alter your duties to ensure there is no risk of harm to patients. This will need to be a continuing dialogue as your condition progresses. The Disability Passport developed by the RCN’s Peer Support Service will be useful in recording discussions and changes to working arrangements. Some may require a variation of your contract of employment (e.g. if you reduce your hours on a permanent basis). [www.rcn.org.uk/peersupport](http://www.rcn.org.uk/peersupport)

If you feel the time is approaching when you will need to take time off sick or leave work, take advice from your RCN representative, read your employer’s relevant policies and then speak to your manager. RCN Online Advice can be found here: [www.rcn.org.uk/get-help/sick-leave-and-sick-pay](http://www.rcn.org.uk/get-help/sick-leave-and-sick-pay) (accessed 24/8/18)

There will come a time when you know that you are no longer able or willing to continue working. If you pay in to an occupational pension, you may be able to apply for ill health retirement. If your scheme provides this option your eligibility is assessed and if you meet the scheme criteria you can access your entitlement early.


If your pension is with a different provider, a good first step is to look at the scheme policy and obtain a pension forecast that shows what you would get if you were eligible to take ill health retirement.

There are advice services that may be able to assist with your queries:

[www.pensionsadvisoryservice.org.uk](http://www.pensionsadvisoryservice.org.uk)
[www.pensionwise.gov.uk](http://www.pensionwise.gov.uk) (accessed 24/8/18)

You may also want to discuss money matters with an Independent Financial Adviser. As a member of the RCN you are entitled to a complimentary, no-obligation financial review from Lighthouse Financial Advice. [www.lighthousegroup.plc.uk/affinity/royal-college-of-nursing](http://www.lighthousegroup.plc.uk/affinity/royal-college-of-nursing) (accessed 24/8/18)

You may qualify for disability benefits from the Department of Work and Pensions (DWP). The Lamplight Support Service can advise you on this and also identify other potential entitlements and ways to maximise your income. The service is for the nursing family, not just RCN members. More information is available here: [www.rcn.org.uk/lamplight](http://www.rcn.org.uk/lamplight) (accessed 24/8/18)

Additionally, RCN members can access FCA-regulated money and debt advice and assistance with benefits decision appeals from the Welfare Service, part of the RCN Member Support Services. [www.rcn.org.uk/welfare-service](http://www.rcn.org.uk/welfare-service) (accessed 24/8/18)

Alternatively, call RCN Direct for further information on retired membership categories and a referral to appropriate services.
**If you are worried about a colleague**

You may have noticed that a colleague’s behaviour has changed or that they don’t seem themselves anymore. There could be any number of reasons for this, but if they are forgetful and seem confused and struggling with tasks they used to have no problems with, it could be an indication of dementia.

It sounds simple to say, “Talk to them and tell them that they should see their GP,” but what if they don’t seem to be aware of the changed behaviours you are noticing?

The Alzheimer’s Society has the following advice:

*It can be helpful to pick a place that is familiar and non-threatening, so you can talk about it comfortably. It can also help to pick a time when you won’t be rushed. You could also pick a time when the GP surgery is open so that if they feel ready to book a GP appointment, they can do this.*

You might start the conversation by gently asking the person if they’ve been feeling any different from usual or are struggling with anything. It can be helpful to start by showing that you are raising concerns because you care about them and want to offer support.

Remember that there isn’t one approach that is best for everyone, and there isn’t a ‘right’ or ‘wrong’ way to discuss your concerns. You should also consider that they may not react how you expect them to. You should listen to how they respond, and you may need to adapt your approach.

(Alzheimer’s Society, 2018)

As with many situations where you have to broach a difficult subject with someone, think about how you would want to be treated yourself or how you would handle a difficult conversation with a patient. It is possible that your colleague lacks insight into their behaviour or is trying to hide the difficulties they are experiencing.

If your colleague is absolutely resistant to the idea and you remain concerned about their practice, you too have an obligation under the NMC Code of Conduct to raise your concerns with an appropriate person, such as their line manager. You may also feel strongly that you want to inform their GP (if you know who that is). GPs can’t discuss their patients with you, but they can receive information and it is then their responsibility whether to act upon it. It is always advisable to tell the person that you are going to speak to their line manager/GP in advance.

**Useful sources of advice and support**

- **RCN Peer Support Service:** [www.rcn.org.uk/peersupport](http://www.rcn.org.uk/peersupport)
- **RCN Welfare Rights and Guidance team:** [www.rcn.org.uk/welfare-service](http://www.rcn.org.uk/welfare-service)
- **Disability Employment Advisers at Job Centre Plus offices**
- **Dementia UK:** [www.dementiauk.org/understanding-dementia/advice-and-information/](http://www.dementiauk.org/understanding-dementia/advice-and-information/)

(all accessed 24/8/18)
Supporting a member who has been diagnosed with dementia is, in many ways, no different to any other health-related case you will deal with. The fear and stigma surrounding the illness may, however, require you to address issues in different ways.

**Workplace culture**

Firstly – regardless of any actual cases you may be running, you may wish to encourage your employer to sign up to becoming “dementia friendly”. Doing so will help create a culture at work where staff feel able to talk openly about their concerns, confident that their employer will make informed decisions about their employment and not act rashly out of prejudice.

The Alzheimer’s Society encourages employers to become “dementia friendly” and lists the following as reasons why:

- It’s the right thing to do.
- It will help retain staff.
- It will help the organisation become an employer of choice.
- The organisation will provide a more inclusive service.
- It will future-proof the organisation.
- It will contribute to increased productivity.
- The organisation will be fulfilling its legal responsibilities.

(Alzheimer’s Society, 2015)

Full information on becoming a dementia friendly workplace can be found here: [www.alzheimers.org.uk/info/20116/making_organisations_more_dementia-friendly/357/creating_a_dementia_friendly_workplace](http://www.alzheimers.org.uk/info/20116/making_organisations_more_dementia-friendly/357/creating_a_dementia_friendly_workplace) (accessed 24/8/18)

Alongside this, you yourself may wish to become a “Dementia Friend”:

*Being a Dementia Friend simply means learning more about dementia, putting yourself in the shoes of someone living with the condition, and turning your understanding into action.*

From visiting someone you know with dementia to being more patient in a shop queue, every action counts.

(Alzheimer’s Society, 2017a)

Not only will this enhance your clinical practice, but if you are representing someone who may have or has already been diagnosed with dementia, it will give you valuable insight that will help your work with them. If there are a group of you interested in this, it may be possible to arrange a training event rather than each undertaking the learning individually.

Find out how to become a Dementia Friend here: [www.dementiafriends.org.uk](http://www.dementiafriends.org.uk) (accessed 24/8/18)

**Casework**

As with all casework, it is important to be led by the member but you also have a responsibility to ensure members are able to make informed, rational decisions. Many people with health problems that affect them at work feel guilty that, in some way, they are letting their colleagues and their employer down by being a burden. Many feel they ought to resign quickly to make things easier for their manager. This need not be the case! In addition, you will need to be sensitive to the fact that the member you are supporting may lack insight into their behaviour (this can be a symptom of the disease) or may be working really hard to hide the impact it is having. If you feel the member you are representing lacks capacity it is really important that you seek advice from your regional office about how and when to involve their family and carers.

Useful information on assessing capacity can be drawn from the following clinical guides:


There are two key areas where your expertise may be called upon to support and represent a fellow RCN member:

- continuing to work
- leaving work.
Supporting continued employment

A diagnosis of dementia does not automatically mean that someone must leave work. Depending on the extent of the challenges someone is experiencing, they may still be able to make a useful contribution within a team or department or in a different part of the organisation. Above all, speak to the member openly and honestly, and encourage them to be realistic and pragmatic about their capabilities and the support they feel they need. Reassure them that their diagnosis need not mean automatic dismissal. It may help you to look at the RCN’s Disability Passport documentation.

The Alzheimer’s Society reminds us that, when supporting people with dementia, giving them choice and control of their lives, and allowing them to continue to contribute their skills and experience to the organisation, can not only make a difference to affected staff, but bring benefits to the whole organisation (Alzheimer’s Society, 2015).

If the member you are working with has memory issues, it is more important than ever that you document your advice and ensure notes are clear about what needs to be done and who will do it. Ask the member how they want to work with you – this may mean working in a different way, meeting in quiet rooms rather than busy canteens or coffee shops, making notes for the member, or inviting a family member or friend for additional support.

Reasonable adjustments

Reasonable adjustments are required by the Equality Act 2010 (Disability Discrimination Act in Northern Ireland). No doubt you will have supported members in having reasonable adjustments made to their work before. As stated above, this is no different, although you need to be aware of patient safety issues and nursing competencies. Reasonable adjustments for someone with a dementia diagnosis may include:

- changes to the physical environment (e.g. ensuring there is clear signage and labelling, creating quiet spaces, and installing soundproofing or putting up visual barriers to minimise distractions)
- changes to the job specification, reallocation of duties, a change of working hours, or redeployment to another role.

The DWP Access to Work fund may be able to advise on and fund such changes. For more information on Access to Work see www.gov.uk/access-to-work (accessed 24/8/18)

The RCN’s Peer Support service can provide advice on reasonable adjustments: www.rcn.org.uk/peersupport (accessed 24/8/18)

Share your successful adjustments here: www.rcn.org.uk/get-help/member-support-services/peer-support-services/workplace-adjustments-database (accessed 24/8/18)
Case study – the rep’s tale

Jaine first talked to me about her situation when she was waiting for a neurology appointment to come through. She wasn’t sure how to broach the subject with her line manager so her colleague suggested she speak to me first. To be honest I’d never dealt with a case like this before, but then I realised that, really, it’s just like any other health matter someone has at work. There’s such a stigma about dementia though, and I could see she was really worried. After that first conversation I decided to look into dementia more and did the Dementia Friends training that was offered locally. It was quite an eye opener and really made me appreciate the barriers people face pre and post-diagnosis. I think it helped my clinical work as well as my representation work.

I went with Jaine when she went to speak to her manager, who turned out to be really supportive. They agreed to a period of time off and agreed to look into workplace adaptations and the support occupational health could offer. When Jaine returned to work her manager had a number of suggestions as to how she could continue to work safely and effectively. I’d been in touch with the RCN’s Peer Support service to enquire about reasonable adjustments too – they have an excellent guide and are compiling a database of adaptations that others have benefited from. Of course all cases are different, but it was useful to get some ideas. We also sought advice and support from a local charity and from Access to Work – they provided some matched funding for a support worker which really made a difference. I recommended that the manager do the Dementia Friends training too, and they in turn said they would raise the issue with other senior managers. The trust now has dementia friendly status which is great.

Jaine needed to alter her ways of working, duties and hours as time went on until eventually, 12 months post-diagnosis, she and her partner met with me and the line manager to agree her retirement from the trust. She was granted Tier 2 ill health retirement at the first application, probably because her medical evidence was so strong and she had the backing of Occupational Health. It was sad to see her go as she was an integral member of the team, but the time was right and she knew it. She had often expressed her fear of losing that insight and becoming a burden to others. Now she does some volunteering work in a day centre. I’ve been to visit her and can see how much it means to her to still be caring for others.
When the time comes that a member is no longer willing or able to work

The Alzheimer’s Society recommends employers avoid using capability and disciplinary procedures when they can no longer make adjustments or when someone is ready to leave by choice, but follow instead a “dignified exit package and strategy” (Alzheimer’s Society, 2017b). Ideally this should be part of the absence or sickness policy in your workplace, but it may not be.

Ill health retirement

If the member has an occupational pension, they may be able to apply for ill health retirement. If their scheme provides this option, eligibility is assessed by medical advisers and if the scheme criteria are met pension benefits are payable. Some employers also offer a Permanent Health Insurance policy that may provide a short-term income.

The NHS pension scheme offers ill health retirement and RCN Online advice on this can be found here: www.rcn.org.uk/get-help/rcn-advice/ill-health-retirement-nhs-pension-scheme (accessed 24/8/18)

If the member has a pension with a different provider, a good first step is to look at the scheme policy and obtain a pension forecast that shows what might be payable if the eligibility criteria for ill health retirement is met.

There are advice services that may also be able to assist:

www.pensionsadvisoryservice.org.uk
www.pensionwise.gov.uk
(both accessed 24/8/18)

The member may want to discuss money matters with an Independent Financial Adviser. RCN members are entitled to a complimentary, no-obligation financial review from Lighthouse Financial Advice. www.lighthousegroup.plc.uk/affinity/royal-college-of-nursing (accessed 24/8/18)

The member may also be entitled to disability benefits from the Department of Work and Pensions (DWP). The Lamplight Support Service can advise on this and also identify other potential entitlements and ways to maximise income. The service is for the nursing family, not just RCN members. More info here: www.rcn.org.uk/lamplight (accessed 24/8/18)

Additionally, RCN members can access FCA-regulated money and debt advice and assistance with benefits decision appeals from our Welfare Service. www.rcn.org.uk/welfare-service (accessed 24/8/18)

RCN Direct can provide further information on retired membership categories and referral to appropriate services.
6. Information for line managers

If you have noticed that a colleague’s behaviour has changed or that they don’t seem themselves, as their line manager you have a responsibility to find out what is going on, especially if it is affecting patient care or relationships within your team. There could be any number of reasons why this might be, but if they are forgetful and seem confused and struggling with tasks they used to have no problems with it could be an indication of dementia.

It sounds simple to say, “Talk to them and tell them that they should see their GP,” but what if they don’t seem to be aware of the changed behaviours you are noticing or are resistant to seeking help?

The Alzheimer’s Society has the following advice:

*It can be helpful to pick a place that is familiar and non-threatening, so you can talk about it comfortably. It can also help to pick a time when you won’t be rushed. You could also pick a time when the GP surgery is open so that if they feel ready to book a GP appointment, they can do this.

You might start the conversation by gently asking the person if they’ve been feeling any different from usual or are struggling with anything. It can be helpful to start by showing that you are raising concerns because you care about them and want to offer support.

Remember that there isn’t one approach that is best for everyone, and there isn’t a ‘right’ or ‘wrong’ way to discuss your concerns. You should also consider that they may not react how you expect them to. You should listen to how they respond, and you may need to adapt your approach.

(Alzheimer’s Society, 2018)

As with many situations where you have to broach a difficult subject with someone, think about how you would want to be treated yourself or how you would handle a difficult conversation with a patient. Make sure you reassure the member of staff that you will support them to continue working if possible.

Acas has produced a useful guide for managers supporting staff with mental ill health, much of which is applicable in this situation. [www.acas.org.uk/media/pdf/8/i/Approaching-a-sensitive-conversation-regarding-mental-ill-health.pdf](http://www.acas.org.uk/media/pdf/8/i/Approaching-a-sensitive-conversation-regarding-mental-ill-health.pdf) (accessed 24/8/18)

NHS Employers advise:

*It is important for a person working with dementia to still feel as though they are part of the team. Creating a culture where staff feel comfortable to talk about their health freely and where they can discuss the support they may need without prejudice is vital.*

(NHS Employers, 2015)

If the staff member is absolutely resistant to the idea of seeking medical advice and you remain concerned about their practice, you will need to escalate your concerns. If you are a nurse too, you have an obligation under the NMC Code of Conduct to raise your concerns with an appropriate person and protect patient safety.

You may also feel strongly that you want to inform their GP (if you know who that is). GPs can’t discuss their patients with you but they can receive information and it is then their responsibility whether to act upon it. It is always advisable to tell the person that you are going to speak to their line manager/GP in advance.

Developing ongoing, open and honest communication with a staff member with a diagnosis will make the matter of supporting their continued employment or supporting them when it is time for them to leave work so much easier and more dignified for all.

Whether other members of the team are informed of the staff member’s situation is a matter for them to decide, but openness and honesty at an early stage can be helpful.

**Medical suspension**

If the member of staff does not have a Fit Note yet you feel they are unfit to work, you should seek advice from your HR advisers and Occupational Health service. You may be able to insist on a period of medical suspension, for example while changes to ways of working are agreed. Medical suspension attracts full pay.
Occupational Health advice

Occupational Health (OH) can offer help and advice on keeping well at work. They may have experts who are trained in supporting employees with dementia or know of local services that are available.

When discussing reasonable adjustments it will be helpful to have an OH assessment that identifies the member of staff’s needs.

Disability Employment Advisers and/or Access to Work advisers at the Job Centre should also be approached for support and expertise.

Supporting continued employment

A diagnosis of dementia does not automatically mean that someone must leave work. Depending on the extent of the challenges someone is experiencing they may still be able to make a useful contribution within a team or department or in a different part of the organisation. Above all, speak to the person openly and honestly and encourage them to be realistic and pragmatic about their capabilities and the support they feel they need. Reassure them that their diagnosis does not mean automatic dismissal. As stated above, advice and support from OH, HR and Access to Work/Disability Employment Advisers will be really important.

The Alzheimer’s Society reminds us that, when supporting people with dementia, giving them choice and control of their lives, and allowing them to continue to contribute their skills and experience to the organisation, can not only make a difference to affected staff, but bring benefits to the whole organisation (Alzheimer’s Society, 2015).

Reasonable adjustments

Reasonable adjustments are required by the Equality Act 2010 (Disability Discrimination Act in Northern Ireland). Reasonable adjustments for someone with a dementia diagnosis may include:

- changes to the physical environment (e.g. ensuring there is clear signage and labelling, creating quiet spaces, and installing soundproofing or putting up visual barriers to minimise distractions)
- changes to the job specification, reallocation of duties, a change of working hours, or redeployment to another role.

The DWP Access to Work fund may be able to advise on and fund such changes. For more information on Access to Work see www.gov.uk/access-to-work (accessed 24/8/18)

The RCN’s Peer Support service can provide advice on reasonable adjustments: www.rcn.org.uk/peersupport (accessed 24/8/18)

You may find that you need to provide support to the other members of your team as well. Acas suggests the following:

A manager should be prepared to support the team more than they usually would. This might include being around their team, and having catch-ups with each member on how they are doing. The manager should also make clear that they are available at any time to talk about any concerns or worries a team member may have.

Where an organisation has additional support services (such as mental health first aiders or employee assistance programmes), a manager should also promote these services so staff understand how they may benefit from using them. www.acas.org.uk/index.aspx?articleid=6064 (accessed 24/8/18)

When the time comes that a member is no longer willing or able to work

The Alzheimer’s Society recommends employers avoid using capability and disciplinary procedures when they can no longer make adjustments or when someone is ready to leave by choice, but follow instead a ‘dignified exit package and strategy’. Ideally this should be part of the absence or sickness policy in your workplace, but it may not be.
**Ill health retirement**

If the member of staff has an occupational pension, they may be able to apply for ill health retirement. If their scheme provides this option, eligibility is assessed by medical advisers and if the scheme criteria are met pension benefits are payable. Some employers also offer a Permanent Health Insurance policy that may also provide a short-term income.


If the member of staff has a pension with a different provider, a good first step is to look at the scheme policy and obtain a pension forecast that shows what might be payable if the eligibility criteria for ill health retirement are met.

There are advice services that may also be able to assist:
- [www.pensionsadvisoryservice.org.uk](http://www.pensionsadvisoryservice.org.uk)
- [www.pensionwise.gov.uk](http://www.pensionwise.gov.uk)
  (both accessed 24/8/18)

The member of staff may want to discuss money matters with an Independent Financial Adviser. RCN members are entitled to a complimentary, no-obligation financial review from Lighthouse Financial Advice.

Otherwise, details of local Independent Financial Advisers can be found here:
- [www.unbiased.co.uk](http://www.unbiased.co.uk) (accessed 24/8/18)

The member of staff may also be entitled to disability benefits from the Department of Work and Pensions (DWP). The Lamplight Support Service can advise on this and also identify other potential entitlements and ways to maximise income. The service is for the nursing family, not just RCN members. More info here:
- [www.rcn.org.uk/lamplight](http://www.rcn.org.uk/lamplight) (accessed 24/8/18)

Additionally, RCN members can access FCA-regulated money and debt advice and assistance with benefits decision appeals from our Welfare Service.

RCN Direct can provide further information on retired membership categories and referral to appropriate services.
Case study – the manager’s tale

If I’m honest I knew something was amiss with Jaine quite a while before she came to talk to me, but I didn’t know what to do and the demands of my job didn’t really give me much time to stop and think about how to approach her. So I buried my head in the sand, hoped it was a “woman’s thing” and that it would get better in time. When she asked to see me I could tell she was nervous, so I was pleased when she brought Kris, her RCN rep, along with her. It’s always a good idea to have an extra pair of ears in the room for emotionally charged conversations such as this one. I was happy to agree a period of leave while she went for tests and could see that the worry of the situation was affecting her greatly.

While she was off I approached Occupational Health and HR for advice. I also did some research myself online and found the web pages of the Dementia UK and Alzheimer’s Society really informative. However, at the end of the day this was just like any other capacity issue and I was determined not to let prejudice about dementia alter my way of working with Jaine. She wanted to stay at work for as long as possible and I was happy to support that.

She’s been such an asset to the team for such a long time, I didn’t want to lose her too soon. We discussed the ways her role would need to change at first and also started to think about future changes too. It helped that she was so open and honest with me and so happy to consider making such changes.

We had expert help from external agencies which was really helpful – they have the knowledge and experience that I could never have. I was guided by trust policy and also made enquiries about how we could prepare for her eventual departure. Making sure her pension arrangements were in place was really important – I now encourage all my team to understand their pension and to make use of their Total Reward Statements.

When the time came for us to plan her departure I wanted to make sure it was a celebration of all she had achieved – so she could leave her career on a high note despite her illness.

In this time the trust has signed up to be a Dementia Champion – it makes sense for our patients and visitors as well as for our staff.
References


