Welcome to today’s webinar

• Now that you have joined, you will notice that you are on mute.

• It will stay on this slide and you will not hear anything until approximately 10:05am.

• If you have any questions throughout the webinar, please write them in the Private Chat section located in the below right panel.

• There will be an opportunity to have your questions answered at the end.

• This webinar will be put on the NDAA website afterwards (with no audio).

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#dementiaseenandheard
Learning Disabilities and Dementia - Enhancing Care & Support

Presenters: Beth Britton and Sarah Ormston

Follow us on Twitter: @bethyb1886 @SarahOrms & DementiaLD
Who are we?

Beth Britton @Bethyb1886
Freelance Campaigner, Consultant, Writer and Blogger specialising in ageing, health, social care and dementia

Sarah Ormston @SarahOrms
Sarah currently oversees Health for people supported in MacIntyre (around 1600 Children, Young People and Adults), as well as Manager for the Dementia Project (DHSC funded project).
What we will talk about today

In this webinar, we will talk about the pioneering work MacIntyre have done through their Department of Health funded ‘Dementia Project’, which aims to improve awareness of learning disabilities and dementia, support a timely diagnosis and train professionals.

We will explain the value to frontline staff of having access to our ‘Wellbeing for Life’ toolkit, and give practical tips for any health and social care provider who is supporting people with a learning disability and dementia, or who are at risk of developing dementia.
Beth Britton
Freelance Campaigner, Consultant, Writer and Blogger

Former carer to my dad who had vascular dementia for 19 years.

Dad went 10 years without a diagnosis, and spent the last 9 years of his life in 3 different care homes.

Dad died in April 2012 aged 85.
Beth Britton
Freelance Campaigner, Consultant, Writer and Blogger

**Campaigner:** Public speaking and media work.

**Consultant:** Training and mentoring of health and social care staff and work with stakeholder organisations.

**Writer:** For newspapers, magazines, specialist journals and online publications.

**Blogger:** Author of D4Dementia and guest blogger for numerous publications.

I’ve worked with MacIntyre for 4+ years and I’m the external consultant for the Dementia Project.
About MacIntyre

We provide learning, support and care for more than 1,500 children, young people and adults who have a learning disability and/or autism, at more than 170 services across England and Wales.
Supporting people as they get older: the challenges to MacIntyre as a provider
The Solution: MacIntyre’s “Dementia Special Interest Group”

- Staff from across MacIntyre who support people who have or are at risk of dementia
- Share best practice
- Provide peer support
- Solution focused
- Guests, including industry experts and families
- An internal web-based noticeboard for resources
- A social media internal forum
- Created resources of Top Tip Booklets
It keeps on growing...
Delivering better dementia care for people with a learning disability

Department of Health
Voluntary Sector Investment Programme
Innovation, Excellence and Strategic Development Fund
The MacIntyre Dementia Project Team
Aims of the project

1. To **raise awareness** of dementia among people with a learning disability, their families and professionals to better understand their condition and future care.

2. To help people with a learning disability **receive a timely diagnosis** of dementia.

3. To create **learning opportunities** for professionals to provide better care for people with learning disability living with or at risk of dementia.
How Beth and MacIntyre have worked together

Beth has worked with the Dementia Special Interest Group (DSIG) since 2013, and has since become a key partner and the consultant for MacIntyre’s Dementia Project.

Beth is a member of the **Dementia Project Steering Group** and shares her expertise to ensure that the Dementia Project is at the forefront of dementia practice.

As part of her role, Beth advises the Dementia Project on the tools and resources we produce – she was fundamental in helping to write the content of the **Wellbeing For Life toolkit**, and has since undertaken a full review of the toolkit.

Beth also runs **roundtable events** for MacIntyre staff to help support their training and development. We will be publishing a guide to roundtable events and a case study in the next few weeks.
What is Wellbeing for Life?

• Wellbeing for Life is a Toolkit of resources and eLearning.

• The Toolkit aims to provide access to appropriate resources and information to support people who have dementia, are at risk of dementia, or are growing older.

• The Toolkit has a range of resources including eLearning to enhance knowledge; resource documents and booklets in a variety of formats including easy read; numerous internet references and reports.
Wellbeing for Life covers several topics that are organised into themes:

- Theme Zero: An Introduction
- Theme One: Fit for the Future
- Theme Two: Person Centred Approaches
- Theme Three: Health and Wellbeing
- Theme Four: Good Support
- Theme Five: The Dementia Pathway
- Theme Six: End of Life Care

Under each of these themes, we have a variety of different modules to assist in developing understanding and knowledge in each topic.
Modules in Wellbeing for Life

- Five Ways to Wellbeing
- Challenging Discrimination and Stigma
- Eating and Drinking
- Person Centred Care and Support
- Life Story
- Access to Healthcare
- Epilepsy in Later Life
- Reducing the Risk of Falls
- Safer Swallowing
- Pain and Distress
- Dignity and Respect
- Promoting Independence and Safety
- Who Else Can Help?
- Learning Disability and Dementia
- Signs and Symptoms
- Getting a Timely Diagnosis
- Treatments

- Changed Behaviour – including 11 mini books
- A Dementia Friendly Environment
- Validation and Reality Orientation
- Living Well with Dementia
- The Emotional Impact of Dementia
- The Emotional Impact of Dementia: Supporting Peers and Friends
- An Introduction to End of Life Care
- Exploring End of Life Care
- Loss, Change and Grief
- Talking about Death and Dying
- Advance Care Planning
- Continued Care and Support for Everyone After Death
- Care in the Last Days and Hours of Life
- Providing the Best Support
Changed behaviour booklets

1. Verbal Aggression
2. Physical Aggression
3. Repetition
4. Paranoia and Accusations
5. Walking
6. Restlessness
7. Anxiety
8. Tearfulness – Being Emotional
9. Wakefulness – Disturbed Sleep
10. Losing or Hoarding Objects or Items
11. Losing Sexual Inhibitions
What Staff Have Said…

“Very helpful. Doing this as a team was of benefit as we discussed and heard ideas about the content of the training. There was information that will be put into action by the team and all in all the whole team had a positive take on it”

“Modules were very informative and helpful. Also the layout of the modules was very fresh and bright – interesting”

“I thought the layout of the modules was very clear and accessible - nice colours too. The two modules we did were beneficial for those we support and have triggered lots of ideas on how we can aid the people we support”

“I think the eLearning was useful in the way it was presented. The eLearning was presented in a very visual way, my preferred learning style. Useful to understand the use of colours”

“Good suggestions about how to do, and what is, 'life stories' and creative ways to produce them. Also good advice on different colours and items in rooms for people with dementia and autism”

“Completing these modules as a group has been very beneficial in that it has provoked discussion in how to use the information/ knowledge gained to our specific service”
Accessing ‘Wellbeing for Life’

- You will find some resources already available on our website, including case studies and top tips guides.
- The latest edition to our resources is a guide to poly pharmacy, which we published last month.
- We plan to release as many resources as we can that will be free to download in the future.
- At the present time, we are looking for further funding to be able to disseminate our resources more widely.
- If you are a healthcare professional we would be keen to hear from you if you are interested in having access to our module materials.
Supporting a Person – Part 1

In the next section of the Webinar, we will give practical tips for any health and social care provider as well as families who are supporting people with a learning disability and dementia, or who are at risk of developing dementia.

The first thing to think about is: How do we help a person with a learning disability receive a timely diagnosis?
What is meant by Timely Diagnosis?

NHS England 2015 defines a ‘Timely’ Diagnosis as:

“When the patient wants it OR when the carers need it”

A person with a learning disability is less likely to receive a timely diagnosis of dementia.
Considerations around diagnosis
So, why get a diagnosis?

• To rule out other conditions
• To rule out other possible causes of confusion
• To provide a person with dementia with an explanation of their symptoms
• To allow a person with dementia to access treatment, information and support
• To allow a person with dementia to plan and make arrangements for the future
• To allow a person to have control over their own life and future as much as possible.
The Diagnosis Process for people with a Learning Disability

Some facts to consider:

• The diagnosis pathway for dementia is **exactly the same** as for people without a learning disability. However, **how the steps are undertaken will vary**.

• Accurate diagnosis of dementia in people with a learning disability, particularly in the early stages, remains difficult and there is a **high risk of an inaccurate or missed diagnosis**.

• Often **repeated assessments over time** are the only reliable way of assessing change.

• Some **reasonable adjustments will need to be made** to ensure that the person is able to access the assessments needed, for example, having a blood test may require an approach unique to the person.
The Diagnosis Process for people with a Learning Disability

• Some of the tests are not suitable for those who have limited communication skills or a profound learning disability.
• For people with a learning disability, diagnosis often relies on reports and written records and information from family and staff.
• Too often a diagnosis of dementia is made without the proper investigations being undertaken. An essential part of a definitive diagnosis requires investigations to be undertaken to rule out conditions that have similar symptoms but can potentially be treated and/or cured.
• Brain imaging, e.g MRI and CT scans, are less reliable for people with a learning disability.
• Availability of assessments and treatment across the UK is inequitable.
Our challenges around Timely Diagnosis

- Diagnostic overshadowing
- Late diagnosis and inaccessible dementia pathways
- Additional health needs – sometimes unknown and unmet
- Increased risk factors related to lifestyle
- Lack of accessible information
- Limited records of past history and experiences
- Growing older and living with older parents and carers
- Attitudes and assumptions of others
Enabling more Timely Diagnoses in the future

Over the years several recommendations have been made about baseline screening and monitoring for people with Down’s Syndrome. Reasons for these recommendations include:

• The importance of establishing an **accurate baseline of skills and abilities** for people with a learning disability.

• Having a baseline of skills and abilities while the person is healthy provides **evidence of change(s) in function**.

• Self-reporting by people with a learning disability is limited compared to people who do not have a learning disability. Information is often provided by staff and/or family, therefore a **clear and accurate written record is required to show changes**.

• Change is always measured from either a past baseline of evidence or, if this is not available, then the **presenting skills and abilities become the baseline to measure change and deterioration**. This may mean a significant delay in diagnosis and therefore any treatment.

• A baseline of skills and abilities between the ages of 21 to 30 years is preferable and allows for **post maturity changes**.
Supporting a Person – Part 2

For the next section of the webinar we want to focus on **awareness, care and support** looking at how we support the person, their family, peers, friends and the health and social care professionals who are involved in their life.

We are going to look at:
- Support before and after diagnosis
- Acceptance of a diagnosis
- Fears
- How we explain dementia
- Difficulties with understanding
- Day-to-day life
- Practical tips for anyone wanting to help the person
- Progression
- Maintaining relationships
- Interacting with someone who has advanced dementia
- Coping
- Key skills for health and social care professionals
- Tips for services that aren’t learning disability specialists
When Dementia is Suspected – Feelings and Emotions

• When a person is developing dementia, it is likely to be a difficult time for the person, their family, peers, friends and the staff supporting them.
• The changes associated with dementia can be complex and may seem baffling to everyone until a formal diagnosis is made.
• Being mindful of everyone’s feelings, emotions and the adjustments that are happening in their relationships is vital.
• Before a diagnosis of dementia is made, it is important for the people supporting the person to consider the implications of a diagnosis of dementia. By planning in this way and talking to the person undergoing the dementia assessment, the people supporting the person can encourage them to think about their needs and wishes.
• Key questions include whether the person wants to know their diagnosis when it is made, and if they want anyone else to be told.
Supporting a Person after a Diagnosis of Dementia – Informing Peers and Friends

• If the person wants their peers and friends to know about their diagnosis, those supporting the person will need to help them to decide if they want to give that information themselves, or if they want someone else, like a trusted staff member, to lead those interactions.

• Where someone else is informing peers and friends about a person’s dementia diagnosis, this needs to be done sensitively and in a dignified and respectful way.

• Those supporting the person, their peers and friends may need to carefully plan how this is done, and be prepared to introduce information in stages and to repeat information as needed.

• There is no specific duration for this – it may take minutes, hours, days, weeks or months.
Acceptance of a Diagnosis

- Some people view a diagnosis of dementia as a relief because it explains what is happening to the person.
- Other people have more questions than answers after a diagnosis and may struggle to come to terms with this new reality that they, or someone they are close to, is experiencing.
- For family members, particularly parents, it can be especially difficult to hear that their loved one has been diagnosed with dementia as a younger person – despite a lot of awareness-raising in society, many people still only associate dementia with older age groups.
- Within a household or group of peers or friends, professionals can expect to see many different reactions. These are unique to each individual, and require professionals to help each person navigate their way through what they are feeling.
Coping with the Fears Associated with Dementia

• When supporting a person who is diagnosed with dementia to inform their peers and friends, professionals need to be **calm, reassuring** and be **confident** in having up-to-date knowledge of dementia.

• As a professional, you may be feeling emotional yourself, but you should never allow your own feelings to project onto the people you support.

• At all times professionals should **avoid using stigmatising language** or giving information that is misinformed or misguided.

• Many people associate a **sense of loss** with dementia, and in more acute situations, feel **grief** even though the person is alive. Professionals should be aware of these emotional responses and be prepared to deal with them in a compassionate way.
Explaining Dementia to a person with a Learning Disability

- The **MacIntyre easy read resources** to explain ‘What is dementia’ offer a format that is designed to explain dementia to a person with a learning disability.
- The leaflets explain to the person what the brain does, what dementia is, what can happen, how the person may feel and what those involved in the person’s life can do to help the person with dementia.
- It is important to remember that this resource will need to be used differently with different people. Some people may want to know all of the available information, whilst others may only want to know some of it, and others may reject the information completely.
- You may also want to consider running or hosting an accessible **Dementia Friends** session using the resources we helped the Alzheimer’s Society to create.
Difficulties with Understanding

• Despite the best efforts of health and social care professionals to explain a dementia diagnosis, the person who has been diagnosed may not understand their diagnosis. Equally some of their family, peers or friends may not understand either.

• Depending on how advanced the person’s dementia is their brain may be unable to comprehend what a diagnosis of dementia means. Equally, peers or friends with severe or profound learning disability may be unable to fully appreciate what dementia is and what a diagnosis means.

• Whilst denial may be frustrating for professionals, it is important to remember that everyone has their own way of coping with life-changing news. There is no right or wrong.
Activities of Daily Living

• Whilst dementia inevitably changes many things in a person’s life, trying to **keep day-to-day routines as regular as possible** for everyone is usually the most positive approach.

• Creating a big fuss around a person who is diagnosed could make them feel ‘singled out’ in an unhelpful way, or make their peers and friends feel ‘left out’. Professionals need to **find the right balance** using their experience of all the people involved.

• Where extra help or support is needed for the person with dementia, professionals should use their judgement and knowledge of the people they support to make sure they get the balance right between meeting the needs of the person with dementia and ensuring their peers and friends have **equal access** to the support that they need.
How Family, Peers and Friends can help

• Concerned and caring family, peers and friends may want to help the person with dementia.
• Practical help should be encouraged and supported – it is likely to be beneficial for all concerned.
• Think about the best ways to support the person with dementia. Ideas include:
  – Helping the person to maintain hobbies or activities that they enjoy
  – Bringing fun and laughter into their life through shared interests like sports or music
  – Attending events together to provide mutual companionship
  – Sharing special meals, celebrations or trips out together
  – Reminiscing with the person through the creation and/or use of life story resources
As a Person’s Dementia Progresses

• Given that dementia is progressive and terminal, the person is likely to deteriorate. This will happen in different ways and within different timescales for each person.

• **Family, peers and friends may find deterioration even more upsetting than the initial diagnosis.** Professionals need to use their judgement in relation to how much peers and friends can cope with seeing and experiencing before their own quality of life is impacted.

• Where there are concerns about how peers and friends are coping, professionals need to consider what is in their best interests, and how to structure and support the time peers and friends spend with the person who has dementia.

• **Making small changes to the time and space people have to interact with each other may be all that is needed to help everyone enjoy their time together again.**
Maintaining Relationships Throughout a Person’s Dementia

• Dementia is known to be a very isolating condition; as a person deteriorates that isolation often increases.

• **Helping a person to maintain contact and quality time with their family, peers and friends is vitally important.**

• If the person with dementia needs to move to different accommodation, professionals should encourage peers and friends from their former home to **keep in touch through visits, sharing hobbies and activities, attending events like birthday parties or exchanging cards or gifts.**

• Peers and friends might also like to use **digital technology** to keep in touch - ways to do this include making films about shared interests that can become part of the person’s life story resources, and sending emails and photos with news.
Interacting with a Person who has Advanced Dementia

• Everyone involved in the person’s care and support may need to be **creative** in how they interact with a person who has advanced dementia, and proactive in encouraging others to do likewise.

• If the person is quite frail, **think about activities that are soothing.** Ideas include:
  – Stroking hands or holding hands
  – Singing with the person
  – Talking about shared interests, eg sports, music or films
  – Looking at photos together
  – Watching TV or having a ‘movie night’ and watching a favourite film together
  – Helping with practical tasks, like making the person comfortable in their chair or bed, or making them a drink or some food that they enjoy.
When Family, Peers and Friends are Struggling to Cope

- It is possible that family, peers and friends may find it difficult and eventually impossible to cope with seeing someone they care about living with dementia.
- If they no longer want to have contact with that person, their decision has to be respected and professionals will need to support them to continue their life in whatever way makes sense to them.
- Professionals need to think about how they provide additional support to the person with dementia in this situation to reduce any distress that they may feel.
Qualities Health and Social Care Professionals need to Show

• It is important throughout a person’s dementia, from pre-diagnosis to end-of-life, that professionals are sensitive to the many emotions that accompany dementia for everyone whose lives are touched by it.

• Qualities professionals will need to demonstrate include:
  – Being non-judgemental
  – Adaptable
  – Creative
  – Understanding
  – Reassuring

• All professionals involved in supporting the person with dementia, their family, peers and friends, should work together as a team to help everyone to maintain their relationships in whatever ways they are comfortable with and for as long as they want.
Tips for Services that aren’t Learning Disability Specialists

• We know that some people who are living with a learning disability and dementia may be moved from a specialist LD service, like supported living, and into a traditional aged care home after a diagnosis of dementia.

• Tips for professionals supporting a person with a learning disability and dementia in a service that doesn’t specialise in learning disability support include:
  – **Offer age-appropriate support.** The person with a learning disability may be the youngest person in your service, so ensure you offer support that is generationally appropriate – the person may have very different tastes in music, food, clothing, hobbies, interests and numerous other areas of life to the people that they are living alongside.
  – **Upskill your staff in learning disabilities.** There are key specialisms involved in supporting a person with a learning disability, including areas like Positive Behaviour Support.
  – **Draw on person-centred practices.** Staff who are highly skilled in person-centred practices and able to create great interactions with the person will be vital to that individual’s ability to live well with their learning disability and dementia. If staff don’t currently have the required level of skill, offer further training and support.
For the last section of the webinar we want to talk in depth about personal relationships with the help of one of our Dementia Project Assistants, Rachel, who has helped us compile the following content about a very special friendship of hers.
Meet Alison and Rachel

- Rachel and Alison had been friends for over 30 years
- Living together as house mates
- Working together and spending free time together
- Doing what best friends do

![Photo of Alison and Rachel]
Personal Impact of Dementia - Alison and Rachel’s Story

https://www.macintyrecharity.org/our-work/supporting-people-with-dementia/macintyre-dementia-project/
A brief snippet of Alison’s life

• Alison was a lady living with Downs Syndrome
• She was in her mid 40s when she received a diagnosis of Alzheimer's disease
• Her life had dramatic changes which happened very fast
• This is where Rachel started to see significant changes within her friend and their relationship
A day in the life of Alison and Rachel

A “typical” day for Rachel and Alison would have involved:

• Having breakfast **together** in the flat they shared
• Walking to work **together**
• Spending a working day **side by side** in a café and bakery
• Going home to catch up on the soaps/ listening to music **together**
• Cooking dinner/ house jobs **together**, taking it in turns and routines
The Impact of Dementia – “The Initial Stages”

After Alison's diagnosis:

• Rachel was seen more on her own
• Alison still attended work but her days become shorter and less active (a different pace)
• Rachel needed time to offload her thoughts and emotions – as did Alison
• Alison needed more care and attention – as did Rachel
• Things had dramatically changed for the ladies
The importance of advocating

Staff helped to ensure that the ladies *spent quality time with each other* so Rachel continued to feel important in Alison's life.

It was also important to Alison that they continued to spend that quality time together.

As Alison’s dementia progressed, more support was needed for both ladies.
What stayed the same in times of change?

• Nothing could take away the bond Rachel and Alison had.
• Alison's needs changed but their friendship remained as strong as ever.
• We had to be mindful and creative in how we continue to support their friendship and not let it get lost.
The role of staff

• Making sure Rachel was aware of what was happening in Alison’s life and how her dementia was affecting Alison’s activities of daily living – in a way that made sense to Rachel
• Making sure the rest of the flatmates had an understanding of what was happening and how things were constantly changing
• Having honest conversations
• Upskilling staff to have an understanding of what will happen and the progression of dementia e.g. End of Life Care
Alison’s Progressive Dementia

- Alison began spending more time at home in her flat.
- Adapting Alison's environment was necessary (bedroom changes).
- Work came to an end due to Alison's health.
- All of this had a massive impact on Rachel, Alison and their friendship.
The final days and hours

- The importance of staying at home: ‘If she goes, I go!’
- Rachel had a fear of ambulances/hospitals but developed an understanding of how important this was
- Alison had to be moved to a hospital for specialist care and support in her final days and hours
- Rachel was with her as much as possible in this time
- Music had a big impact, in particular a Westlife song
Rachel’s continued commitment to Alison

- Rachel will talk to people about Alison's health and share their story, which she will tell with passion and confidence.
- Rachel feels the need to share this on behalf of Alison and continues to do so.
Thank you

• To Rachel for sharing hers and Alison’s story.
• To everyone supported by, working for, or involved with MacIntyre for their support with the Dementia Project.
• To all the external partners and supporters of the Dementia Project.
• To the NDAA for hosting this webinar and to all of you for joining us today!
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Thank you

We hope you enjoyed today’s webinar.

These are open to everyone, so please forward on the details for future webinars.

*Questions, please email ndaa@alzheimers.org.uk
*From Seldom Heard to Seen and Heard
www.dementiaaction.org.uk/joint_work/dementia_and_seldom_heard_groups
*Slides / past webinars visit ww.dementiaaction.org.uk
*For further webinars please check www.dementiaaction.org.uk/events

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