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What will the next election bring for learning disability nursing?

Christine Walker
is editor of Learning Disability Practice
@RCNi_Christine

With a UK general election set for next year or early 2025, what would be included in your election manifesto for nursing?

I am guessing more of your colleagues being recruited and retained, improved pay, reduced workloads, plus better life chances for people with learning disabilities and/or autism would be in there.

In terms of improving care there have been two recent reports that underline there is still a long way to go, but these reports also offer positive support for you in your roles as learning disability nurses.

NHS England and SUDEP Action have published guidance on reducing the risks faced by people with epilepsy. The new guidance is in memory of Clive Treacey, who had a learning disability and died in 2017, aged 47, after a seizure and cardiac arrest. It follows a campaign, led by Clive's sister Elaine Clarke, highlighting failures in his care, which were investigated in an NHS England-commissioned review. Now Together, the Safer Services Guide and the Clive Treacey Safety Checklist have been published.

In November a Health Services Safety Investigations Body report highlighted the patchy nature of learning disability nursing liaison services and why there needs to be more of you in these roles to improve the clinical decisions being made in hospitals. And with about 17,000 learning disability nurses on the Nursing and Midwifery Council register and about 5,000 of that number working in the NHS in the UK, the rest could well be working in the independent sector or social care.

The latter group is beginning to get more of a profile nationally and not before time. Nurses working in social care deserve better recognition for their work. Now the RCN Foundation is funding the first-ever social care nursing chair at the University of Salford and recruitment is under way.

'Nurses working in social care deserve better recognition for their work'

Further information

HSSIB: Investigation Report: Caring for Adults with a Learning Disability in Acute Hospitals **tinyurl.com/acutecare-adults**

NHSE/SUDEP Action: Together, the Safer Services Guide and the Clive Treacey Safety Checklist **tinyurl.com/safer-services**

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Can new training opportunities fix the shortage of learning disability nurses?

A new course pays students to train as learning disability nurses and demand for places is high – the approach could increase the nursing workforce

By Erin Dean
health journalist

How to boost numbers in the shrinking learning disability nursing workforce in the UK is an ongoing concern.

In England, the number of learning disability nurses employed by the NHS dropped from 5,553 in 2009 to under 3,000 (2,971) by summer 2023, according to NHS Digital.

The Nursing and Midwifery Council (NMC) lists 37 universities with approved preregistration learning disability nursing degree programmes.

Educational routes

However, a number of these universities have discontinued their learning disability undergraduate nursing courses, including the University of Sunderland and the University of East Anglia – the latter said a drop in student numbers left the course unviable. But there are other routes into the profession, including four-year degree apprenticeships, two-year master's degrees and nursing associate training, which can be topped-up with a shortened degree apprenticeship.

There is now also a new educational route being offered by one university in Plymouth, in a bid to train more much-needed learning disability nurses of the future.

The question is, can this new approach help to get education for learning disability nursing back on track?

Plymouth Marjon University's programme splits the traditional three-year training into two different elements, during which students receive a wage and do not pay fees.

Preparing for practice

The first part, called ASPIRE and funded by Health Education England, involves a seven-month postgraduate certificate (PG Cert) programme called 'preparing for practice'.

During this time students gain 750 practice hours, complete year one nursing competencies and earn a band 3 salary.

Students then move on to the second part, which is a two-year MSc preregistration learning disability nursing programme. This is an apprenticeship with fees and band 4 salary paid by employers.

Plymouth Marjon University says its ASPIRE approach is the 'first of its kind', and the first 15 students started part one in February 2023, with five more joining in September. The second cohort of 12 is due to start in January 2024. The course is set to be extended into mental health nursing and adult nursing.

Claire Langman, associate dean for nursing and health sciences at the school of health and well-being at the university, says NHS England tasked the nursing school with developing a new preparation programme that could find potential learning disability nurses who may not have the opportunity to study otherwise.

'Our university has strong values around community, social justice and social mobility,' she says.

'So it was about finding individuals who felt passionate about getting into nursing but hadn't been able to do so for one reason or another: it was at the wrong time, they've got young children, couldn't afford to or weren't in the right place.'

The students, who have degrees or foundation degrees come from a wide variety of backgrounds in and outside health, Ms Langman says. She sees the ASPIRE part as a 'traineeship' to give students solid experience of what learning disability nursing involves.

Boosting numbers

The new course is part of efforts by the sector as a whole to boost numbers into learning disability nursing, as numbers have fallen.

While adult, children and mental health nursing numbers are on an upward trajectory, learning disability nurses on the register have mainly fallen, dropping from 17,172 in 2017-18 to 16,840 in 2022-23.

Before this course, south west England had only one learning disabilities programme in Bristol.

Plymouth Marjon worked closely with NHS employers and partners across the region – who recruit the applicants – to develop a model that would bring in the future workforce that they needed.

NHS Devon deputy chief nurse Susan Masters says the programme was allowing the region to 'develop local, homegrown talent' to benefit local patients and their families.

Employers told the university that they needed staff with a strong understanding of neurodiversity, and this is a key element of the programme, says Ms Langman.

Further information

Care Quality Commission (2022) Experiences of Being in Hospital for People with a Learning Disability and Autistic People. **tinyurl.com/CQC-ld-autism-experience**

NHS (2017) Nursing Careers: Learning Disability Nurse. **tinyurl.com/NHS-ld-nurse**

Nuffield Trust (2022) Mental Health and Learning Disability. **tinyurl.com/NT-mental-health-ld**

Plymouth Marjon University (2023) ASPIRE: Preparing for Practice. **tinyurl.com/PMU-aspire**

RCN (2021) Connecting for Change: For the Future of Learning Disability Nursing. **tinyurl.com/RCN-connecting-change**

'It was about finding individuals who felt passionate but hadn't been able to do nursing for one reason or another'

Claire Langman, associate dean for nursing and health sciences at Plymouth Marjon University

'The ASPIRE programme is almost like a traineeship,' she says. 'We worked hard to make sure we could capture the 750 hours and give students a taste of what learning disabilities nursing is about.

'We hope that the retention on the MSc will be high because they've already been exposed to everything in part one. Interest has been high, we could fill the places ten times over.'

The university is waiving the PG Cert fee for the students, which it says demonstrates its commitment to supporting aspiring learning disability nurses.

Innovative approach

A Royal College of Nursing (RCN) report in 2021 highlighted a steep drop in applications for learning disability nursing courses, particularly in England, which were 45% lower in 2019 compared to 2016.

RCN professional lead for learning disability nursing Jonathan Beebee welcomes the innovative approach developed in Plymouth.

While numbers of students on traditional BSc three-year courses remain well below the level they were before 2016 (when the nursing bursary was removed), apprenticeship and master's degrees are an increasingly popular route into the profession, Mr Beebee says.

'Those two options are topping the numbers up to get the number of students in learning disability nursing close to where they were in 2016,' Mr Beebee says.

Way of the future

'The apprenticeship style route is the way of the future. It is a way of getting people who have the values to be a learning disability nurse and the academic ability to study, but they need that financial support to help them through their training.'

Working closely with employers, as Plymouth Marjon has done, will help produce the future workforce needed, Mr Beebee says.

'We have got to look at what they are doing with ASPIRE in Plymouth and see if we can do that elsewhere in the country,' he adds.

'Improving the lives of people with learning disabilities is my passion'

Sandra Van Meurs (pictured), from east Cornwall, had long harboured a dream of being a learning disability nurse but never thought she would be able to afford it until she came across an advert for the ASPIRE programme.

She is now a student on the first cohort and heading for a career that otherwise would not have been possible.

The 47 year old has worked in education roles with children with special educational needs and learning disabilities, most recently in giving career advice, for many years.

'I came from a working-class family, left school without A-levels, and university never seemed an option at that point,' she says.

'After I got a foundation degree and master's in social sciences in my thirties, I looked into learning disability nursing but it wasn't affordable.

Learning disability liaison service

'But then this advert about the course popped up on Facebook one night and I just thought: "Wow, what an opportunity". It wouldn't have happened without this course.'

Ms Van Meurs now spends four days a week at Derriford Hospital, Plymouth, as part of a learning disability liaison service and the fifth day on study leave.

'It is challenging, managing work, studies and my life and family,' Ms Van Meurs says. 'You have to be committed and organised.

'But improving the lives of people with learning disabilities is my passion, so it keeps me motivated.'

End of life care planning for people with learning disabilities

Nurses are key to ensuring that service users' wishes on end of life care are not rushed or missed

By Pavan Amara
nurse, midwife and health journalist

More than half of all people with learning disabilities will die before they reach 65, prompting researchers to call for radical changes in the way they receive end of life care, an area that research indicates is poorly understood.

People with a learning disability are less likely to experience an 'expected death' – identified as being when staff had expected it to happen three months or more before the death – according to researchers.

This suggests there is a perceived lower level of need for end of life care in this population, which means that symptoms may not be managed as well as they should be and end of life planning could be rushed or missed altogether.

Berkshire Healthcare NHS Foundation Trust primary healthcare lead nurse for learning disabilities Mary Codling says that healthcare staff across settings need to get better at recognising when a person with learning disabilities needs end of life care.

Advance care planning

She and others argue that advance care planning, which begins before illness occurs and lays out wishes for life and death, is the best way forward.

'I went into a care home to do an assessment on someone because she wasn't well,' says Ms Codling. 'When I got there, I was told that for the past two weeks she had admissions into hospital and pneumonia. There was something in her look. I said to the staff that she might be dying.

'In the end, I phoned the GP and yes, she was end of life – but no one had told the staff in the care home.'

Meeting people's needs

Ms Codling says once staff at the care home knew this, a multidisciplinary team could meet the person's end of life needs.

She developed a pathway that helps staff give good end of life care to people with learning disabilities.

Another tool called Probabilities of Life Expectancy (POLE) was developed in 2017 by St Anne's Community Services, which helps carers to determine the stages of life a person with learning disabilities has reached.

'But advance care planning is different to that, it can start at any time,' Ms Codling says. 'We don't need to wait until that person is terminally ill. It can include life planning and be done every year, so if someone changes their mind about something, then we can do that.

'Then while talking about life, other questions come about, things such as: "When you die, where would you like to be buried?"'

Advance care planning should account for a person changing their mind, states NHS England. The question of mental capacity will affect some people but those close to them can help with this.

'If someone can't consent or doesn't understand, you would be looking at a best interests meeting with people who know that person well,' Ms Codling says. 'They can tell you what that person would like.'

Some people may not want to talk about death, but others want to plan the details while being able to do so, she says.

People may not wish to discuss certain things and this should be respected and recorded, points out the NHS guidance.

'There was one woman and it was important to her to plan for what happened to her pet budgie after she died,' Ms Codling says. 'Yet others don't want to hear a word about it.'

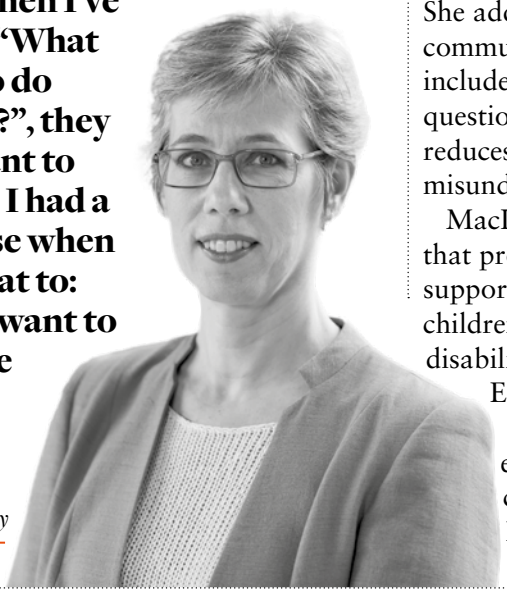
Kingston University professor of intellectual disability and palliative care Irene Tuffrey-Wijne led the Victoria and Stuart Project, which finds ways for people with learning disabilities to plan for the end of their life.

Professor Tuffrey-Wijne says advance care planning is as much about life as it is about death. 'In a way you're not planning for death but the time that you're still alive,' she says.

'It's good to think about phrasing questions to reflect that. I know that when I've asked people "What do you want to do before you die?", they often don't want to think about it. I had a better response when I rephrased that to: "What do you want to do when you're still alive?"'

'I know that when I've asked people: "What do you want to do before you die?", they often don't want to think about it. I had a better response when I rephrased that to: "What do you want to do when you're still alive?"'

Irene Tuffrey-Wijne, professor of intellectual disability and palliative care, Kingston University



Person-centred care for clients at the end of life
rcni.com/my-way

Clear communication

She adds that clear communication – which includes phrasing questions correctly – reduces the potential for misunderstanding.

MacIntyre is a charity that provides learning and support for adults and children with learning disabilities across England and Wales.

Its family engagement consultant is Nicola Payne. She says

‘I was told that for the past two weeks she had admissions into hospital and pneumonia. There was something in her look. I said to the staff that she might be dying’

Mary Codling, primary healthcare lead nurse for learning disabilities at Berkshire Healthcare NHS Foundation Trust

that although advance care plans may exist, they are not always used.

For example, a Public Health England study found that the death rate from the COVID-19 pandemic was six times higher in those with learning disabilities compared to the general population.

‘Maybe advance care plans were there during COVID-19 but not followed,’ she says.

‘That’s a worry because people who died wouldn’t have had their wishes understood.’

She adds that, although death can be a taboo subject, it is easier to break bad news – for example, that a person’s condition is life-limiting or terminal – if their preferred way of communicating is used.

‘If the person communicates in a way that is unfamiliar, in sign language for example, you would need to learn it or get in someone who knows it.’

Nurses should also make sure the person understands what has been said. ‘Don’t assume that the person understands,’ Ms Payne says.

‘Allow for their processing time and reflection. Sometimes when we deliver bad news we think: “Right, I’ve told that person that they’re terminally unwell. I’ve done my job. I’ve walked away, I can breathe.”

But has it really been understood by them?

‘Even if you’re sure it has been understood, revisit it the next day. Say to them: “Our conversation yesterday, how do you feel about that?”, and “Did I use any words that you didn’t understand?” Try to remain as jargon-free as possible.’

Giving bad news

Ms Payne says that too often she has seen staff direct the bad news to everyone in the room apart from the person it affects.

‘It frustrates me,’ she says. ‘That person is the one receiving, for example, a cancer diagnosis. So looking at them is about respecting them.’

She adds that many staff in general settings don’t have experience of working with people with learning disabilities, but should be brave and say that. ‘You don’t have to pretend you know everything,’ she says.

‘Just say to their advocate or another appropriate person: “Can you support me in communicating this to this person?” Ask for their help.’

RCN professional lead in learning disabilities and neuroscience nursing Jonathan Beebee says that hospital, hospice and end of life staff need to be supported to learn more about the needs of people with learning disabilities.

‘At the moment, if someone with learning disabilities has a terminal

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Leaving life workshops help spark discussion of end of life wishes

In Hertfordshire, community learning disability nurses and other staff invite adults with learning disabilities to ‘leaving life’ workshops. These last approximately five hours to allow a slow pace of discussion on end of life wishes.

A 1:1 or 1:2 staffing ratio is used with each attendee so that key information is not missed.

A one-page profile is created, which summarises what is important to each person, where they want to be cared for, how to support them and how they would like to be remembered. People also discuss the things they would like to do while still alive.

Source: NHS England (2017)

Advice on advance care planning for people with learning disabilities

- Understand an individual's vocabulary about death: rather than using terms like 'dying' and 'end of life', a person may refer to 'that place in the sky'. Use their language to talk about things
- Prepare for people to have bad memories of loved ones dying. For example, if a parent has died, a service user might become emotional and want to talk about that first – even years after their death – so reassure them
- Set up workshops on life planning: rather than waiting for someone to become unwell and giving them an advance care plan, workshops can help normalise these discussions in groups

Source: Mary Codling, primary healthcare lead nurse for learning disabilities, Berkshire Healthcare NHS Foundation Trust

illness, there would be a debate about what services can best meet their needs,' he says.

'Are they better off in a place where there are other people with learning disabilities and learning disability nurses?

'Or would they be better in end of life care support provision? They'll have end of life skills in one setting but the learning disability skills are in the other.'

Part of the problem is that there are not enough nurses specialising in learning disabilities who are trained to meet end of life care needs.

Since 2009, England has experienced a 42% decrease in the number of registered learning disability nurses.

'We've known for a long time that there's a declining number of learning disability nurses in the NHS and on the Nursing and Midwifery Council register,' Mr Beebee says.

'That's the biggest concern, because we need nurses with specialist skills and knowledge in this area. The care can be complex for some people.'

Ms Codling, who has been a nurse for more than 30 years, says that it can be emotional when a service user dies.

'You've spent a long time with them and got to know them, especially when it comes to caring for children,' she says.

'I've worked with people who died quite young. I know it's important to speak to colleagues, have a regular review every week and make sure they're doing okay too.

'When people are busy, they often forget to say that basic: "How are you?" to the people they're working with.'

'We support some amazing people. We can't help but become emotionally attached to them'

Jonathan Beebee, RCN professional lead in learning disabilities and neuroscience nursing

Further information

King's College London (2021) LeDeR: Learning from Lives and Deaths – People with a Learning Disability and Autistic People. **tinyurl.com/KCL-ledr**

NHS England (2017) Delivering High Quality End of Life Care for People Who Have a Learning Disability. **tinyurl.com/NHSE-ld-care-delivery**

NHS England (2022) Universal Principles for Advance Care Planning (ACP). **tinyurl.com/NHSE-acp-universal**

The Victoria and Stuart Project **www.victoriaandstuart.com**

Professional boundaries

While maintaining professional boundaries is important, staff are also human.

'We support some amazing people,' says Mr Beebee. 'We can't help but become emotionally attached to them.

'Learning disability nurses will often be involved with people for a long period of their life.

'There is a place for professional boundaries, but humanity is what makes our job and it's common for nurses to experience bereavement.'

He says that nurses should not feel guilty for experiencing grief and some practical steps can sometimes help.

'That person and their family would want you to celebrate their life in death,' he says. 'If appropriate, you can attend the funeral and pay your respects.

'It is a hard one because we're often experiencing feelings of loss, so how do we grieve, let go, and convert that into a celebration of that person? Talk about it, it's not unprofessional to have feelings.'

If you know someone we should interview or profile email ***clare.lomas@rcni.com****, call 020 8872 3161 or* 𝕏*@rcni_clarelomas*

Learning disability nursing careers: what's not to love?

There are many pathways you can take for a varied and rewarding career in learning disability nursing

By Lynne Pearce
health journalist

With multiple career options – including lecturing, research, becoming a nurse consultant or advanced practitioner, there has never been a better time to be a learning disability nurse, says Michael Brown, professor in the school of nursing and midwifery at Queen's University, Belfast.

'You have the opportunity to work with children, adults, older people and those with a range of complex and multiple health issues, all needing knowledgeable, skilled, kind and compassionate learning disability nurses,' he says.

'It's exciting and challenging. What is there not to love about a career like that?'

Professor Brown challenges any perceptions that learning disability nursing is the poor relation to other nursing fields. 'It's never been a Cinderella service,' he says. 'It's a fundamental misrepresentation, but that's how people choose to portray it.

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'It's more to do with the lack of value placed on people with learning disabilities as citizens and service users. As a consequence, that's the value that's placed on the people who work with them professionally.'

Currently 36 universities across the UK and Ireland offer learning disability nursing courses, says Professor Brown.

'Over the past few years, some made strategic business decisions to disinvest in those programmes – but it relates to NHS England and not Scotland, Wales, Northern Ireland or the Republic of Ireland.'

New programme

Some universities are beginning to offer courses again, says Professor Brown. Among the most recent is a new programme launched last summer at Plymouth Marjon University. This started with an initial 15 students, with a further 17 expected to join them.

In two parts, the programme enables students to trial learning disability nursing before committing to the full degree. The first section – preparing for practice – takes seven months, with students undertaking practical, classroom and online learning.

Successful completion leads to part two, a two-year MSc pre-registration learning disabilities nursing programme, with a focus on neurodiversity.

Among the aims is addressing the shortage of learning disability nurses. Latest data from the Nursing and Midwifery Council (NMC) show that numbers continue to decline, with 16,840 learning disability nurses registered up to March 2023 – a decrease of 0.7% on the previous year and the only field to report fewer registrants.

In contrast, the NHS Long Term Workforce Plan, published earlier this year, is committed to a 46% rise in learning disability nursing training places.

To attract more learning disability nursing students, every avenue should be explored, Professor Brown believes.

'In an area of practice that possibly wouldn't be people's first choice – adult or children's nursing is more likely – any route in needs to be developed and made available, with more work needing to be done to promote them,' he says. This work includes graduate entry or associate programmes and conversion courses.

In the future, a changing demographic and more complexity will add to the challenges faced by learning disability nurses. 'There needs to be more investment in education and development to ensure the nursing workforce of the future has the knowledge and skills necessary to meet the needs of this population,' says Professor Brown.

The research nurse looking into sexual health

A longstanding interest in sexual health has driven Emma Stripe's career in learning disabilities.

'It's looking at how we can support people with learning disabilities to have safe and fulfilling relationships, developing their sexual identity. I don't think it's something we do very well,' says Ms Stripe.

She is researching her PhD into the experiences of community learning disability nurses who provide sexual health support for their adult clients. 'It's important my work benefits my colleagues working in the field and isn't something that's abstract,' she says.

After qualifying in 1997, Ms Stripe worked in a variety of settings, including inpatient, community and residential. But in 2015, successfully applying for a fellowship programme with the National Institute for Health and Care Research changed the course of her career.

Initially she completed an internship, before a two-year predoctoral programme, designed to support people who want to start or advance a career in health and social care research methodology

'I knew I wanted to influence policy and understand some of the barriers faced by learning disability nurses,' she says. 'While I could go back to practice and work with individuals to make a difference, I thought could I do that more broadly?'

She joined the University of Huddersfield in 2020, where she is a lecturer and researcher. 'It's essential to have learning disability nurses involved in research,' says Ms Stripe. 'It raises our profile. Most learning disability nurses I've spoken to have an area of special interest, but don't have the confidence to apply for funding.'

'It's essential to have learning disability nurses involved in research'

Emma Stripe

While historically she believes nurses have not been taught enough about research, that is changing, with learning disability nursing students at her university doing a literature review as a final piece of work. 'Students are becoming more familiar with the language of research and it's not as intimidating,' says Ms Stripe.

Sharing innovation across the community is vital. 'We need to be the voice of authority about how people with learning disabilities should be cared for,' she says. 'But at the moment, we're under-represented in research.'

The learning disabilities lecturer

Although Sam Abdulla knew he wanted to move into education at some point in the future, an opportunity arrived to become involved in academia just a year after qualifying.

'It was already in my mind to become a lecturer, but that was a long way down the line,' says Mr Abdulla, who is now a learning disabilities lecturer at Edinburgh Napier University, the same place where he began his degree in 2009.

During his first post in a residential unit, Mr Abdulla successfully applied for a one-day-a-week secondment at the university. This was followed by an NHS Education for Scotland (NES) scholarship, which provided him with a mentor, plus funding towards a master's degree. Throughout he stayed in touch with the university on a casual contract.

After switching to a role in a community learning disability team, another part-time university secondment became available, which he did for around a year, while continuing to work in clinical practice.

'More and more the work at the university became what I was involved in,' Mr Abdulla recalls. 'It made sense I looked at making that my substantive position, with a secondment back out to clinical practice.'

With support from the school's dean, his contract was 'flipped' and he was brought into the university, eventually working just one day a week in the NHS.

'I've been able to travel the world'

Sam Abdullah

About five years ago, he decided to move to the university full time. 'It has afforded me some brilliant opportunities, almost beyond my wildest dreams,' says Mr Abdulla. This includes support to finish his master's degree and begin a doctorate.

'I've also been able to travel the world to talk about learning disability nursing,' he says. Through the Erasmus scheme, he has worked with universities in Poland, Sweden, Romania, Norway, England and Ireland, alongside visiting Singapore.

'There are two days that I love more than anything in the academic year,' says Mr Abdulla. 'The first is day one, when everyone arrives bushy tailed and ready to hit the road. The second is when I watch the students graduate. I've been fortunate enough to make that journey with them, seeing them achieving wonderful things throughout their training. As they march across the stage, all I can think of is all the wonderful things they're going to do.'

The learning disability liaison nurse

For learning disability and autism liaison nurse Serena Jones, the variety of her role is among its main attractions.

'No day is the same,' she says. 'I also enjoy watching someone improve who's been unwell, and working with families, who can sometimes face difficult or sad times.'

End of life care for people with learning disabilities has become a real passion. 'Over the years I've developed a big interest in it,' says Ms Jones, who qualified in 1997.

'I love my job – every day I learn something new'

Serena Jones

'How do we get it right? What does that look like? We need to make sure that the voice of the person with the learning disability is heard, understanding what their wishes might be. The final part of someone's journey should be the best it can be, so they're comfortable and don't suffer.'

After working in various roles in specialist units, outreach and the community, Ms Jones joined Liverpool University Hospitals NHS Foundation Trust in 2016. Her team won the learning disability category at the RCN Nursing Awards in 2019 for its transformative work.

Day to day, her role involves working with inpatients and outpatients, including emergency admissions and those having planned treatment or investigations, such as scans, and making reasonable adjustments to improve their experiences of care.

She also sees her role as empowering general nurses and staff to have the skills to support someone with a learning disability. 'It's about having the confidence to support someone who may have complex health needs, alongside communication difficulties,' says Ms Jones. 'I love my job. Every day I learn something new.'

Further information

National Institute for Health and Care Research (2023) NIHR PFellowship Programme. **tinyurl.com/NIHR-fellowship-programme**

NHS England (2023) NHS Long Term Workforce Plan. **england.nhs.uk/publication/nhs-long-term-workforce-plan/**

NHS (2017) Learning Disability Nurse. **tinyurl.com/NHS-ld-nurse**

NHS Scotland Careers (2023) How to Become a Learning Disability Nurse. **careers.nhs.scot/explore-careers/nursing/learning-disability-nurse**

Plymouth Marjon University (2023) University Addresses Shortage of Learning Disability Nurses in England with Revolutionary New Programme. **tinyurl.com/PMU-ld-nurses**

Why you should read this article:

- To be aware of communication challenges often experienced by people with learning disabilities
- To recognise how communication challenges for people with learning disabilities may be compounded by the growing use of digital technology
- To consider various communication strategies and tools that you could use to support people with learning disabilities

Communication challenges for people with learning disabilities in the digital age

Joanne Blair

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Abstract

Healthcare provision relies on effective communication, since this can enable information to be shared, develop therapeutic relationships and improve health outcomes. However, many people with learning disabilities experience significant issues with expressive and receptive communication, and these issues are likely to be compounded by the growing use of digital technology. This article outlines factors that affect communication for people with learning disabilities during healthcare encounters, including communication challenges they may experience in relation to accessing health information and using digital technology. The article also explores strategies and tools nurses can implement to address these challenges and ensure effective communication with individuals.

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Keywords

communication, communication difficulties, diversity, learning disability, nurse-patient relations, professional, reasonable adjustments, telehealth

COMMUNICATION IS a dynamic and cyclical process that involves a message being transmitted, received and understood (McCabe and Timmins 2013). It is essential to human interaction and makes people feel seen, heard and understood (Money et al 2016). It is a vital part of life that is crucial to well-being (Daly 2017).

Healthcare provision relies on effective communication, particularly because people often seek support from healthcare professionals at a time when they are vulnerable, stressed or anxious. Dithole et al (2017) described communication as crucial for nurses to share information and develop trusting and caring therapeutic relationships with individuals and families. Effective communication can empower individuals to engage with their care and therefore improve their health outcomes.

People with learning disabilities can experience significant challenges with communication – although they will have widely varying communication abilities and needs, since a learning disability is unique to the individual (Smith et al 2020). Generally, the more severe the learning disability is, the more challenging communication becomes (Iacono et al 2019). People with learning disabilities

may experience issues with expressive communication (the ability to express oneself, verbally and/or non-verbally through the use of facial expressions or body language) and receptive communication (the ability to understand other people's verbal language and/or their non-verbal cues) (Beukelman and Mirenda 2013, Marrus and Hall 2017).

Smith et al (2020) suggested that communication issues may arise for people with learning disabilities because communication skills are typically developed through social interaction and they have fewer opportunities than the general population to develop these skills, since they tend to socialise in smaller groups and mix mostly with other people with learning disabilities and the professionals who support them.

The coronavirus disease 2019 (COVID-19) pandemic led to restrictions on human interactions, which made communication increasingly challenging for everyone. These restrictions and the new means of communication implemented in response have likely compounded the inequalities that people with learning disabilities experience in accessing and receiving healthcare services (Chadwick et al 2023).

This article provides an overview of the factors that affect communication for people with learning disabilities during healthcare encounters. It discusses the challenges that this group may experience in relation to accessing health information and the growing use of digital technology. The second part of the article explains what nurses can do to address the challenges described in the first part and meet the communication needs of people with learning disabilities.

Communication challenges

During healthcare encounters, communication with people with learning disabilities may be affected by a range of factors related to the person with a learning disability, the healthcare professional, the healthcare environment and the organisation, many of which are shown in Box 1.

Accessing health information

It is well documented that people with learning disabilities often experience challenges in accessing and understanding health information (Osborne et al 2013, Mastebroek et al 2014, Oosterveld-Vlug et al 2021). These challenges include finding clear and trustworthy health information, understanding how to use health information and what needs to be learned from it, and having the appropriate health information for managing one's health.

Chinn (2017) recognised that low health literacy is one factor in the poorer health outcomes and higher mortality rates among people with learning disabilities compared with the general population. Health literacy is an area of concern not only for people with learning disabilities, but also for the population as a whole. In England, Rowlands et al (2015) identified a mismatch between the complexity of health materials and the skills of working-age adults, with 43% of adults in the general population being below the literacy level required to understand these materials.

Health promotion materials often require reading skills that people with learning disabilities may not possess (Scott and Havercamp 2016). Oosterveld-Vlug et al (2021) acknowledged that low health literary levels make it challenging for people with learning disabilities to manage their health. According to Alshammari et al (2018), communication issues are the most significant barrier to people with mild learning disabilities accessing and using health information.

It has been suggested that people with learning disabilities are not given adequate information about their health compared with the general population (Alshammari et al 2018). Furthermore, during the COVID-19 pandemic, learning

Key points:

- Communication is crucial for nurses to share information and develop trusting and caring therapeutic relationships with individuals and families
- People with learning disabilities often experience challenges in accessing and understanding health information, and are likely to need assistance with using digital technology
- Taking time to talk to people with learning disabilities and/or to their family carers is crucial to determine each individual's preferred communication methods
- Nurses should adapt their communication based on the individual's needs and abilities – for example by slowing down the speed at which they speak, providing sufficient time for the person to respond and actively listening

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disability nurses had to adapt much of the information that was made available to the general population so that it was suitable for people with learning disabilities (Desroches 2020).

Using digital technology

Developments in technology have enhanced communication and assistive technology has enhanced the support provided to various groups, including older people, those with disabilities and people with learning disabilities (Boot et al 2018). During the COVID-19 pandemic, digital communication platforms were a 'lifeline' for many people, and they have become part of the means of communication that people routinely use (Chadwick et al 2023). However, for people with learning disabilities, digital technology can add further complexity to an already confusing and exclusionary world, and most of them are likely to need assistance to access and use it (Boot et al 2018).

Article 9 of the Convention on the Rights of Persons with Disabilities (United Nations 2006) calls for appropriate measures to ensure that people with disabilities have equal access to information and communications technologies and systems. Information technology is increasingly part of daily life (Larsson-Lund and Nyman 2020), yet there is evidence of a digital divide between people with and without learning disabilities (Krysta et al 2021). This is due not only to each person's abilities but also to social and environmental determinants such availability of funds to purchase equipment, housing situation and access to the internet (Chadwick et al 2019, 2023).

There is little research into the number of people with learning disabilities who have access to a computer or into their ability to navigate screens, search engines, digital tools and social media platforms. Lunsky et al (2022) discussed concerns for the mental well-being of adults with intellectual disabilities during the COVID-19 pandemic because of the risks associated with digital technology such as disinformation, cyberbullying and victimisation, particularly because these individuals may lack an understanding of nuances and/or the ability to think critically. It remains to be seen whether digital communication can offer the same level of interaction as a face-to-face communication and whether healthcare encounters that take place online can be adapted to suit the needs of people with learning disabilities.

Box 1. Factors affecting communication with people with learning disabilities during healthcare encounters

Factors related to the person with a learning disability include:
- Nature and severity of their learning disability
- Cognitive ability, for example their ability to understand, retain, process and use information presented to them
- Presence of sensory impairments, for example if they have a hearing or visual impairment
- Availability of their preferred communication methods, for example Makaton or the Picture Exchange Communication System

Factors related to the healthcare professional include:
- Communication skills
- Willingness to engage with people with learning disabilities
- Experience of working with people with learning disabilities
- Level of self-awareness
- Preconceptions and biases about people with learning disabilities

Factors related to the healthcare environment include:
- Ease of access to, and familiarity of the person with, the setting where the healthcare encounter takes place
- Physical layout of the setting, for example how comfortable it feels, whether it provides privacy, the lighting and the level of noise
- Busyness according to time of day, for example the environment may be particularly busy and noisy during meals or medicine rounds

Factors related to the organisation include:
- Staffing levels
- Staff mix
- The organisation's priorities, for example whether it prioritises achieving tasks over spending time communicating with individuals
- Power balance, for example there is a need for senior managers to provide adequate support for front-line staff who are working with people with communication issues, and to recognise the experience and/or training needs of these staff
- Availability of funding for training to help staff develop their communication skills – in general and specifically for communicating with people with learning disabilities

(Adapted from Daly 2017)

Meeting people's communication needs

Martin et al (2010) undertook a literature review on communication between nurses and people with learning disabilities who communicate non-verbally. They identified three main themes:

- Knowledge of the person with a learning disability – people who know the person well will be better equipped to understand their non-verbal cues.
- Mismatch of communication ability between the nurse and the person with a learning disability – a nurse with limited experience of working with people with learning disabilities may lack the skills required to communicate effectively with them.
- Knowledge of communication – the more knowledgeable the nurse is about communication, the more comfortable they are likely to be when talking with a person who communicates non-verbally.

This demonstrates the need for nurses to adapt their communication based on the individual's needs and abilities – for example by slowing down the speed at which they speak, by providing sufficient time for the person to respond, and by being actively aware of non-verbal cues as well as what is being said (Martin et al 2012).

Effective communication with people with learning disabilities starts with a thorough assessment of each person's communication abilities and needs. Taking time to talk to the person and/or to their family carer is crucial to determine the person's preferred communication methods. If the person does not communicate verbally, alternative methods can be used (Wilder et al 2015), for example gestures, head or body movements and vocal sounds. These forms of communication are generally specific to the individual, so using them requires getting to know the person (Griffiths and Smith 2016).

Providing accessible information to people with learning disabilities is crucial for obtaining their informed consent (Cithambarm et al 2021). The easy-read format was created to help people with learning disabilities understand important information – for example about their health, rights, work or gaining skills. It uses pictures to support text written in succinct and straightforward language (Cabinet Office and Disability Unit 2021). Much evidence supports the use of easy-read information, but health information is not always available in easy-read format (McClinchy et al 2011, Hamrosi et al 2014, Chinn 2020). The person may need support to use easy-read information (Sutherland and Isherwood 2016) and that support is usually provided by family carers, but they may lack the knowledge needed for, or be uncomfortable with, discussing health information.

Communication is affected by environmental factors such as those listed in Box 1. Healthcare settings that specifically care for people with learning disabilities are not always designed to promote effective communication (Stans et al 2017). Reasonable adjustments may be needed to ensure communication is not compromised by environmental barriers – for example, appointments may need to be arranged at the start or end of the day, when the environment is quieter, or in a location the person is familiar with, such as their local health centre or day care centre (Wilson et al 2022).

Nurses also have a role in ensuring that the person's communication needs are regularly re-assessed and that their communication abilities and needs are recorded and shared with everyone involved in their care (Doody et al 2023).

Communication tools

Heifetz and Lunsky (2018) highlighted that staff in mainstream hospital settings can find it challenging to obtain information about a person with a learning disability. They suggested that a clear care plan and the use of communication tools such as health passports can significantly improve the quality of care, reduce readmissions, and alleviate stress and anxiety for all involved.

The health passport is one of several well established communication tools that nurses can use to elicit essential information from a person with a learning

FURTHER RESOURCES

Mencap – Communicating with people with a learning disability
www.mencap.org.uk/learning-disability-explained/communicating-people-learning-disability

disability and communicate with them effectively (Woods and Standen 2021). Augmentative and alternative communication uses a range of strategies and tools to help people who do not communicate verbally or whose verbal communication is limited. These tools and strategies may be simple letter or picture boards or sophisticated computer-based systems (Communication Matters 2023). Box 2 lists some examples of tools for communicating with people with learning disabilities.

Digital technology

Digital communication platforms are increasingly used in healthcare provision. Appointments can be arranged remotely, with the advantage that individuals who find it challenging to attend appointments in person can still be seen and regularly reviewed. Therefore, nurses need to adapt to digital technology, develop their technical competence and digital literacy skills, and become confident and proficient in the use of digital platforms. Nurses also have a role in promoting optimal communication and the development of effective relationships with people with learning disabilities when healthcare encounters take place online. This includes making reasonable adjustments – for example, spending time before the encounter ensuring that the person is comfortable and confident in using the digital platform – and advocating on behalf of the person (Kim and Lee 2021).

Box 2. Examples of tools for communicating with people with learning disabilities

- Hospital passport – a booklet completed by the person, with support from family or carers if necessary, to relay essential information about themselves to hospital staff (www.mencap.org.uk/advice-and-support/health-coronavirus/health-guides)
- Picture Exchange Communication System (PECS) – an example of an augmentative and alternative communication tool that uses pictures to convey meaning (pecs-unitedkingdom.com)
- Makaton – a communication tool using speech signs and symbols (www.makaton.org)
- Signalong – a communication system using signs (www.signalong.org.uk)
- Talking Mats – a picture-based communication tool (www.talkingmats.com)
- Widgit symbols – pictures used to support the understanding of text (widgit.com)

Health information is readily available online, but not all of it is accurate, relevant and accessible. Nurses have a role in ensuring that online health information accessed by the person with a learning disability is appropriate and is presented in a way that they will understand. Having knowledge about the person, their background, their cognitive abilities and their support systems is crucial to protect them from misinformation and information overload (Smith et al 2020).

Self-awareness and reflection

To communicate effectively with people with learning disabilities, nurses need to develop self-awareness and reflect on their practice. Patel and Metersky (2022) defined reflective practice as a determined attempt to view an experience alongside personal values and beliefs. Reflection offers a structure to enhance nurses' understanding of their practice by identifying gaps in their knowledge (Goulet et al 2016). Barchard (2022) emphasised the important role of reflection in nursing practice, since it encourages nurses to think critically about aspects of performance in their professional role, with the aim of using this critique to acknowledge their strengths and areas for improvement. Nurses may increase their self-awareness as a result of reflective practice, which can lead to various improvements, for example in how the nurse communicates with others.

Factors affecting communication that are related to the healthcare professional include preconceptions and biases about people with learning disabilities (Box 1). Reflection offers an opportunity for nurses to explore their preconceptions and biases and how they react to specific situations. The Nursing and Midwifery Council (2018) expects registrants to avoid making assumptions and to be aware of how their behaviour can affect and influence the behaviour of others. Reflective practice and high levels of self-awareness will support nurses to reflect on how they communicate

with people with learning disabilities and recognise what they can do to enhance communication (Martin et al 2012).

Conclusion

People with learning disabilities often experience communication challenges in their encounters with healthcare professionals, including when accessing health information and using digital technology. Nurses can use various tools to assist them in communicating effectively with people with learning disabilities.

They also need to develop self-awareness and reflect on their practice. As healthcare provision increasingly relies on digital technology, nurses who care for people with learning disabilities need to ensure reasonable adjustments are made and advocate on their behalf. It remains to be seen whether digital communication can offer the same level of interaction as a face-to-face communication and whether online healthcare encounters can be adapted to suit the needs of people with learning disabilities.

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Why you should read this article:

- To recognise the potential benefits of physical activity for people with learning disabilities
- To learn about a study that explored the barriers and supports experienced by adults with learning disabilities when attempting to access fitness centres
- To consider how nurses can support inclusive physical activity for people with learning disabilities

Understanding the barriers experienced by adults with learning disabilities when accessing fitness centres

Natasha Antonietta Spassiani, Sam Abdulla, Andrew Hiddleston et al

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Abstract

Background Many people with learning disabilities are unable to access fitness centres due to these facilities often being inaccessible and non-inclusive.

Aim To examine the barriers and support experienced by adults with learning disabilities when attempting to access fitness centres.

Method Participants were recruited from community organisations and fitness centres in a large city in Scotland. A total of 13 adults with learning disabilities and 12 fitness instructors participated in the study. Data were collected via a series of discussion groups using the nominal group technique.

Findings The study identified several themes that were either barriers or supports to people with learning disabilities being able to visit fitness centres and take up exercise. These themes included the availability of assistance, getting to and from fitness centres, physical challenges, and the environment of fitness centres.

Conclusion Assistance was the main support required by people with learning disabilities when accessing fitness centres, while fitness instructors required education to understand the needs of people with learning disabilities. Nurses have a health promotion role in educating fitness centre staff about how to interact with people with learning disabilities.

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Keywords

accessible information, clinical, dual diagnosis, health promotion, learning disability, lifestyles, mental health, well-being

Background

Research has shown that people with learning disabilities experience barriers and health inequalities that can have significant negative effects on their physical and mental health, for example not being able to access healthcare services or experiencing stigma when receiving care (Emerson and Baines 2011). In addition, people with learning disabilities are likely to die at a much younger age than people without learning disabilities, especially those with severe learning disabilities (White et al 2022).

Physical activity can have an important role in helping people to lead healthy lifestyles and preventing them from developing health conditions such as diabetes mellitus and heart disease (Cleven et al 2020). In addition, people with learning disabilities are more likely to be overweight or obese and have mental health conditions than people without learning disabilities (Buckles et al 2013, Ranjan et al 2017), which emphasises the need for them to have access to inclusive facilities such as fitness centres. Research has found that physical activity can help improve physical and mental health in individuals with disabilities, including those with learning disabilities (Ginis et al 2021). However, people with learning disabilities often do not engage in sufficient levels of daily physical activity to experience improvements in their health (Pierce and Maher 2020).

Charnley et al (2019) emphasised that participating in structured leisure activities can enhance the quality of life of people with learning disabilities. However, there are barriers that often prevent them from engaging in physical activity in their communities (Spassiani et al 2019). These barriers include not being able to access appropriate fitness centres, caregivers' lack of motivation to help people with learning disabilities to participate in physical activity, difficulties with transportation and the cost of participation (van Schijndel-Speet et al 2014, Shields and Synnot 2016). Similarly, while fitness centres may enable people with learning disabilities to have access to equipment and fitness classes, their attendance is often unsustainable in the long-term due to membership and transportation costs (Maine et al 2020).

There has been limited research into the accessibility and inclusivity of fitness centres for people with learning disabilities, despite evidence suggesting that being physically active can have benefits for an individual's physical and mental health (Ginis et al 2021). It is important for nurses to understand how people with learning disabilities experience fitness centres and how such centres can be made more inclusive.

Aim

To examine the barriers and support experienced by adults with learning disabilities when attempting to access fitness centres.

Method

This study was structured around the following research questions:

- What barriers do adults with learning disabilities encounter when attempting to use fitness centres?
- What support do adults with learning disabilities encounter when attempting to use fitness centres?
- What barriers do fitness instructors encounter when trying to help adults with learning disabilities to access fitness centres?
- What support do fitness instructors receive when trying to help adults with learning disabilities to access fitness centres?

Research team

The research team for this study consisted of two university researchers (NAS and SA), a nursing student (LB) and two citizen researchers with learning and/or physical disabilities (AH and KL). The citizen researchers took on leadership roles throughout the project, for example independently leading discussion group sessions. The team worked together to design the project, collect and analyse data, and write this article.

Participants

The study took place in the summer of 2019 and participants were recruited from community organisations in a large city in Scotland. Participants were recruited via snowball sampling, whereby the research team contacted community organisations for people with learning disabilities and fitness centres to identify people who might be interested in taking part in the study. Prospective participants with learning disabilities were required to be adults with some experience with being physically active, while prospective fitness instructor participants were required to be currently employed as a fitness instructor in Scotland.

A total of 13 adults with learning disabilities and 12 fitness instructors participated in the study. The level of physical activity of the participants with learning disabilities ranged from minimal to sometimes engaging in physical activity. For the fitness instructors, their level of professional experience of working with people with learning disabilities ranged from none to limited experience. The fitness instructors worked in a variety of fitness settings in a large city in Scotland, including public and private fitness centres.

Data collection

To collect data from the participants, the researchers used a method called the nominal group technique. This is an accessible and inclusive data collection tool that involves small groups discussing a topic and developing a list of items they feel are important to that topic (Delbecq et al 1975). Once the group members are happy with the list of topics, they vote on which are the most important to them. After the voting is completed, the group counts all the votes to see which items on the list are most important – that is, those topics that attracted the most individual votes.

The nominal group technique is an inclusive way for study participants to take part in data analysis (Gallagher et al 1993). Past research studies have used this technique to assist researchers to gain insightful information from people with learning disabilities on a variety of topics, such as barriers and supports to attending university (Spassiani et al 2017), and providing feedback on medical assessment tools (Spassiani et al 2016).

Data collection was split into two parts by the researchers: part one involved discussion groups for the participants with learning disabilities, while part two involved discussion groups for the fitness instructor participants. The discussion groups were voice recorded.

Discussion groups

Two discussion groups were conducted with the 13 participants with learning disabilities, during which they were asked about their experience of visiting fitness centres. Following general discussion of their answers, two lists were developed:

- A list of the barriers encountered when visiting fitness centres.
- A list of the support available when visiting fitness centres.

The lists were written either by a participant with a learning disability or by a research team member with a learning disability. Once the groups were happy with the lists, voting took place, with the participants asked to vote on their top three topics on each list. The votes were then counted to determine which topics were deemed most important to the group.

Three discussion groups with the 12 fitness instructor participants were conducted by the research team. The participants discussed their experiences of engaging with adults with learning disabilities in a fitness setting and any barriers and/or support they had encountered. The discussion groups were meant to help the participants to develop a list of supports and barriers; however, the participants did not vote on their top three topics due to time constraints. Therefore, the subsequent data analysis used the raw data from the fitness instructors' discussions.

Implications for practice

- Citizen researchers with learning disabilities can meaningfully contribute to evidence-based research
- Health promotion messages for people with learning disabilities that aim to reduce the effects of physical and mental health conditions should include physical activity
- Educating people with learning disabilities about the benefits of physical activity and supporting inclusive physical activity for these individuals should be a priority for healthcare professionals

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Data analysis

Analysis drew from the raw data generated by both sets of participants during the discussion groups and the voting (nominal group technique) undertaken by participants with learning disabilities.

Descriptive statistics were used to summarise the votes generated by the participants with learning disabilities. Axial coding was used to qualitatively analyse the data. The research team then discussed how themes could be identified, described and organised (Corbin and Strauss 1990). The team discussed any disagreements about codes and themes at length until everyone on the team was happy with the identified themes.

Ethical considerations

This project was approved by the ethics board at Edinburgh Napier University in the School of Health and Social Care. All participants provided consent and/or guardian consent to take part in the study. The data were anonymised to protect participants' confidentiality.

Accessible language

This article was co-written with people with learning disabilities and/or physical disabilities. The article was written in accessible language so that people with learning disabilities could understand the study's findings. By understanding how the authors undertook the study and the findings, people with learning disabilities may be able to use this information to address some of the barriers they experience when trying to attend fitness centres in their communities. The terms 'fitness centres' and 'gyms' are used interchangeably throughout this study because both terms were used and understood by the participants. It was hoped that those people with learning disabilities who read this article could share their knowledge with others in the community and 'spread the word' on how to make fitness centres more accessible. This would, in turn, improve the health and mental well-being of people with learning disabilities.

Findings

Barriers for people with learning disabilities

During the group discussions, participants with learning disabilities talked about a variety of topics related to the barriers that people with learning disabilities can experience when visiting fitness centres. Four themes emerged from the voting and were ranked in order of importance: assistance, getting to and from fitness centres, physical challenges, and the environment of fitness centres. The voting results for themes related to barriers to visiting a fitness centre are detailed in Table 1.

Table 1. Voting results for themes related to barriers to visiting a fitness centre

Theme	Topics discussed	Number of votes*
Assistance	» Not having someone to help you at the gym » Not having a social worker to help you take your medicines before you go to the gym » Having someone to ask for help » Having someone to repeat instructions	15
Getting to and from fitness centres	» Having to travel a long way to go to the gym » Not being able to take the bus alone » Not knowing how to get there	11
Physical challenges	» Getting tired » Having difficulties with movements	5
Environment of fitness centres	» Loud music » Bright lights » Hard-to-use lockers	5

*Participants could vote on the same item more than once if that item was particularly important to them

Assistance

The theme of assistance received the most votes, showing that the group members considered lack of assistance to be the top barrier to visiting fitness centres. Participants with learning disabilities spoke about not having someone to help them to use the exercise machines or other facilities such as swimming pools and changing rooms. They also discussed the barrier of not having someone to ask for help when

at the fitness centre, for example nobody being available to repeat instructions when participating in fitness classes. The group members also discussed the importance of knowing if an individual had taken their medicines before going to the gym and how it might not be safe to exercise if a support worker was not present because the medicines might have side effects that interfered with or ruled out exercise.

Getting to and from fitness centres

Participants with learning disabilities discussed how travelling to fitness centres could be a challenge. The group members spoke about how fitness centres were often located far away from their homes. Some participants discussed how they could not take a bus alone and would need someone to accompany them to travel to a fitness centre. Most of the participants discussed how they did not know how to get to the fitness centres and did not have the support available to help them, such as someone to drive them or teach them how to take public transportation independently.

Physical challenges

Participants with learning disabilities spoke about how they would have liked to be more physically active but that they tired quickly when engaging in exercise. Some participants discussed being too tired to think about going to a fitness centre. Others discussed how some fitness classes might be too challenging for them and would require adjustments. However, they were not aware of how to modify the exercises taught in fitness classes, or if the instructor would know how to help them do this.

Environment of fitness centres

The group members discussed how fitness centres were not set up properly to be inclusive of people with various disabilities. For example, some participants spoke about how the music playing in gyms could be too loud, which made it hard to think and hear other people. Others found the loud music in gyms to be overstimulating. Participants also discussed how they found it hard to use the lockers at the gym, as well as being concerned that their belongings might be taken.

Support available for people with learning disabilities

Participants with learning disabilities also discussed the factors that supported them to visit fitness centres. Four themes emerged from the voting and were ranked in order of importance: helpful assistance, positive effects of 'working out', the environment of fitness centres, and getting to and from fitness centres. The voting results for themes related to support available when visiting a fitness centre are detailed in Table 2.

Helpful assistance

Participants with learning disabilities discussed how having useful assistance would aid them to visit fitness centres and take part in classes. For example, some participants spoke about how receiving help to fill out gym membership forms could remove barriers to them joining, as well as accessing equipment, fitness classes and swimming pools. Being able to ask

Table 2. Voting results for themes related to support available when visiting a fitness centre

Theme	Topics discussed	Number of votes*
Helpful assistance	» Having someone to help fill out forms such as those to apply for gym membership » Having helpful gym staff » Having someone to help you 'work out' » Having someone to show you how to use machines	20
Positive effects of working out	» Enjoying feeling fit » Having fun while working out	9
Environment of fitness centres	» Enjoying the music » Having easy access for wheelchairs » Being provided with clear information » Having classes to suit everyone's fitness level	3
Getting to and from fitness centres	» Getting a lift » Living close to the gym so you can walk	2

*Participants could vote on the same item more than once if that item was particularly important to them

gym staff for help with questions about the fitness centre, or about working out or using exercise machines, was seen as a positive support factor by participants.

Positive effects of working out

Participants discussed the positives to exercise, stating that they liked to work out to feel they were in 'good health'. Some participants stated that it was 'fun to work out' and wished that they could be more physically active but were unsure how to achieve this.

Environment of fitness centres

Participants discussed how the environment of fitness centres could contribute positively to their feelings of inclusion. For example, playing music at a lower volume, ensuring accessibility for people using wheelchairs and providing written information in an accessible format were all considered beneficial.

Getting to and from fitness centres

Participants also discussed how getting someone to drive them to the fitness centre was helpful, especially for those who did not know how to travel independently. The group members also talked about how living close to a fitness centre was helpful because they could walk and would not need to rely on anyone to take them or pick them up.

Barriers for fitness instructors

During the three discussion groups conducted with the fitness instructors, the participants developed a list of barriers they encountered when trying to help adults with learning disabilities to use fitness centres. From the list, four themes emerged: lack of training, lack of a person-centred approach, stigma, and managing expectations.

Lack of training

The fitness instructor participants discussed how they were unsure how to make fitness classes inclusive and safe for people with learning disabilities. The participants described often feeling that they lacked training in physical exercises for people with learning disabilities, which made them feel less confident in taking fitness classes or one-to-one exercise programmes. They also discussed their concerns about people with learning disabilities misunderstanding their instructions, which could increase the risk of injuries.

Lack of person-centred approach

The fitness instructor participants discussed how they found it challenging to provide person-centred exercise services for people with learning disabilities. This was particularly true for fitness instructors who worked at private gyms and had to work to a strict time schedule or incur penalties from management. Due to these time constraints, the fitness instructors were under pressure to keep classes running on time and were often unable to talk to or get to know people with learning disabilities. This had implications for the participants, who did not have the time to assess the needs of individuals with learning disabilities or how to support them. In turn, these time constraints meant that people with learning disabilities did not have the opportunity to approach fitness instructors to identify their needs.

Stigma

The fitness instructor participants discussed how stigma could be a barrier to people with learning disabilities engaging with exercise programmes because they might not want to appear 'different' from the rest of the group during classes or gym sessions. The participants mentioned how when teaching people with learning disabilities about exercises or how to use gym equipment the instructors sometimes had concerns about 'doing the wrong thing', which might have led to injuries.

Managing expectations

The fitness instructor participants discussed how it could be challenging to

accommodate everyone (people with and without disabilities) in fitness classes while giving each individual an equal amount of attention. The participants described how they sometimes found it challenging to balance the expectations and ability level of people with learning disabilities with what they hoped to achieve from fitness classes.

Support available for fitness instructors

During their three discussion groups, the fitness instructor participants developed a list of supports they encountered when trying to help adults with learning disabilities to use fitness centres. From the list, four themes emerged: communication, carer support, a person-centred approach, and professional development.

Communication

The fitness instructor participants discussed how knowing how to communicate effectively with people with learning disabilities was a support when including them in fitness classes. For example, some of the participants used visual prompts when explaining exercises. The participants also discussed how they would have liked the opportunity to have further discussions with people with learning disabilities because this might have identified shared experiences, of exercise and 'life in general', which could help develop trusting relationships. The participants also suggested that it might be helpful to meet people with learning disabilities before exercise classes to discuss their needs, but that this was not always possible.

Carer support

The fitness instructor participants recounted how carers could help them to provide support for people with learning disabilities during fitness classes. The participants discussed how carers knew the people with learning disabilities well and would know how best to communicate with them, as well as knowing how to modify exercises so that they were safe. The participants also talked about how carers were able to join people with learning disabilities in fitness classes so that the classes became a shared experience.

Person-centred approach

While the time taken to develop a person-centred approach was identified by some fitness instructor participants as a barrier to including people with learning disabilities in fitness classes, a person-centred approach was also identified as a support. For example, participants discussed how they could use a person-centred approach to help people with learning disabilities to feel relaxed and included by showing them information about exercises, carrying out inductions before fitness classes (for example, to assess an individual's strength or ability), and by having them 'try out' equipment before gym sessions to develop their confidence.

Participants discussed the use of a 'buddy system' during fitness classes to support the inclusion of people with learning disabilities. They also discussed how making changes to the environment of fitness centres and gyms so that they were more inclusive for people with learning disabilities would be beneficial. For example, displaying timetables that detailed the level of exercise classes – such as beginner, medium or hard – was suggested as a way of including people with learning disabilities who could then choose classes that best suited their needs.

Professional development

The fitness instructor participants discussed how they required further education on how to include people with learning disabilities in fitness classes. The participants did not feel adequately prepared to work with people with learning disabilities and felt that additional training and education would help them develop their confidence in this area.

Discussion

In this study, the factor that received the most votes from people with learning disabilities, as a support and a barrier to accessing fitness centres, was assistance,

including assistance by support workers and fitness centre staff. However, the fitness instructors reported not having the training, knowledge or confidence required to support people with learning disabilities to engage in physical activity. Fitness instructors discussed stigma and disability, and how they felt people with learning disabilities may not want to reveal their disability to fitness instructors for fear of being labelled as 'different'.

The fitness instructors also discussed their concerns about causing injury to people with learning disabilities due to a lack of knowledge about how to modify exercises. Nikolajsen et al (2021) found that the physical structure of fitness centres and the unconscious discriminatory attitudes of some staff about people with learning disabilities (ableism) were barriers to people with learning disabilities accessing fitness centres. Ensuring that fitness instructors have access to specific training in adaptive physical activity might enhance their confidence in working with people with learning disabilities and reduce the stigma about disability which in turn might improve the confidence of people with learning disabilities to visit fitness centres.

In this study, the fitness instructors and people with learning disabilities spoke about the important role support workers have in assisting people with learning disabilities to engage in physical activity at fitness centres. People with learning disabilities are more likely to take part in physical activity if they have the appropriate support in place. However, support workers often receive minimal training in the nutrition and exercise required to assist people with learning disabilities to make healthy and balanced choices (Russell et al 2018).

Time pressures on support workers can also limit the ability of people with learning disabilities to engage in physical activity. For example, administration tasks can reduce the time available for support workers to help people with learning disabilities visit gyms (van Schijndel-Speet et al 2014). Similarly, physical activity sessions are often cancelled in group homes, day centres and supported living environments due to staffing shortages (Cartwright et al 2016). In addition, understaffing can mean that there may not be enough support workers available to ensure that offsite visits to fitness centres can be supervised. While it is not the role of fitness instructors to replace support workers, they might be able to help with some roles when people with learning disabilities visit a gym or fitness centre, such as explaining how to use equipment or participate in group activities. In this way, fitness instructors might be able to ensure that people with learning disabilities would not be excluded from participation. However, such a role would require fitness centre staff to undergo appropriate preparation and training.

In this study, people with learning disabilities discussed the importance of having their needs understood and supported to better enable them to attend gyms and fitness centres. Similarly, fitness instructors discussed how they would like to support people with learning disabilities to participate in exercise classes, in addition to learning more about person-centred approaches to use when interacting with these individuals. In the UK, the Equality Act 2010 outlines the responsibilities for organisations to make reasonable adjustments for people with learning disabilities so that access to services is easier and fairer. For fitness centres, this might include providing information about the services they offer in alternative formats such as accessible posters and brochures and not only online, which is how many fitness centres advertise opening times and classes. The lack of access to clear information can cause significant challenges for people with learning disabilities because many do not have access to a computer or to the internet (Spassiani et al 2023). This can limit their independence when accessing fitness centres because they cannot check public transport routes or gym opening times.

The discussion groups in this study also emphasised that not everyone with a learning disability may understand the importance of physical activity for physical and mental health. Many people with learning disabilities are unable to engage with public health campaigns due to difficulties in understanding health promotion messages (Russell et al 2018). Health promotion is central to nursing practice and involves supporting people to engage in a healthy lifestyle to prevent illness and involving them in decision-making about their health; however, many nursing roles do not fully support health promotion activities, instead focusing on health education, which is more concerned with informing people about the facts about health issues (Whitehead 2018).

To provide health promotion for people with learning disabilities, nurses should attempt to be more active in developing healthcare environments that support people to achieve their health goals. In terms of access to fitness and exercise, health promotion might involve nurses supporting fitness centre staff to better understand the needs of people with learning disabilities. Additionally, nurses could seek to educate people with learning disabilities about the positive effects of exercise on their physical and mental health.

Limitations

This study was limited in size and scope and could have been enhanced with further exploration of more diverse locations, and a larger sample size. This would have enabled the researchers to identify other important barriers and supports to making fitness centres inclusive for people with learning disabilities. However, a strength of this study was that it was co-designed and co-produced with people with disabilities, emphasising that people with learning and physical disabilities can form part of a research team to conduct research, analyse findings and contribute to writing an evidence-based research article.

Conclusion

This study examined the opinions of people with learning disabilities and fitness instructors to understand how people with learning disabilities could be better supported to visit fitness centres and gyms and participate in exercise. The findings showed that assistance was the main support required by people with learning disabilities to enhance their access to fitness centres, that staff at fitness centres required education to better understand the needs of people with learning disabilities, and that information about exercise could be provided in various formats to improve inclusivity. Nurses have a health promotion role in educating fitness centre staff about how to interact with people with learning disabilities, as well as in discussing the positive effects of exercise with people with learning disabilities.

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Why you should read this article:

- To recognise the challenges in breaking bad news to people with learning disabilities
- To consider various tools that you could use in your practice to break bad news
- To count towards revalidation as part of your 35 hours of CPD, or you may wish to write a reflective account (UK readers)
- To contribute towards your professional development and local registration renewal requirements (non-UK readers)

Breaking bad news to people with learning disabilities: barriers and tools

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Abstract

Breaking bad news is a challenging aspect of healthcare professionals' roles in any setting. In learning disability settings, specific challenges compound the difficulty of this task. For example, a person who has cognitive difficulties may not understand an abstract concept such as death; the person's family may be concerned that hearing bad news will be too distressing for them; or the healthcare professional may be reluctant to talk about death because of their own beliefs and values.

This article discusses the barriers related to breaking bad news to people with learning disabilities. It also describes several tools – generic and specific to the learning disability field – which healthcare professionals can use to inform and improve their practice in this area.

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Keywords

attitudes to death, breaking bad news, clinical, communication, end of life care, learning disability, nurse-patient relations, patients, person-centred care, professional

Aims and intended learning outcomes

The aim of this article is to support healthcare professionals to develop their knowledge, confidence and skills in breaking bad news to people with learning disabilities. The article is targeted at nurses, nursing associates, healthcare assistants and support workers – referred to throughout as 'practitioners' – who care for people with learning disabilities. After reading this article and completing the time out activities you should be able to:

- Identify the main challenges for practitioners when breaking bad news to a person with a learning disability.
- Discuss why different people have different perceptions of what 'bad news' is.
- Describe various tools designed to support healthcare professionals to talk to people about death and dying.
- Explain the importance of working collaboratively with families and carers when breaking bad news to people with learning disabilities.

TIME OUT 1

What do you think the expression 'breaking bad news' means? What do you consider to be 'bad news'? In your practice, have you come across people whose perception of bad news was different from yours?

Introduction

Bad news has been defined as 'any information which adversely and seriously affects an individual's view of his or her future' (Buckman 1992). This article focuses on breaking bad news in the healthcare context – for example, communicating to someone that they have a life-limiting condition or informing them of another person's illness or death. Breaking bad news is challenging for healthcare professionals in any setting (Bousquet et al 2015) and they cannot always predict the effect the news will have on the recipient, since this will partly depend on the person's understanding and expectations (Baile et al 2000). However, despite these challenges, breaking bad news is a professional duty of nurses. The Nursing and Midwifery Council (2018) makes it clear that being able to have difficult conversations, which includes breaking bad news, is a required proficiency of nurses.

In learning disability settings, practitioners who break bad news to people may have known the person for many years and developed a strong bond with them (Tuffrey-Wijne and Rose 2017). It is important to bear in mind that people with learning disabilities may perceive bad news differently from others. For example, hearing that their day centre is closing may be more difficult for a person with a learning disability than hearing that they have a serious condition, since it may have a more immediate and concrete effect on their life. Each person will have their own perception of what bad news is for them.

Breaking bad news to a person with a learning disability is often complicated by legal and ethical issues with mental capacity and by a desire to protect the individual from distress (Tuffrey-Wijne et al 2013). However, not being given information may be equally distressing for the person. Salander (2002) found that some patients newly diagnosed with cancer experienced anxiety due to a lack of straightforward information and preferred to know the facts. Similarly, Tuffrey-Wijne et al (2010) found that people with learning disabilities were often upset when they were not given any information at all when receiving a cancer diagnosis.

In end of life and palliative care, phrases such as 'having difficult conversations' or 'having challenging conversations' are often used (Costelloe et al 2018, Johnston and Beckman 2019, Macmillan Cancer Support 2022). However, these phrases are ambiguous and people with learning disabilities may not understand them, so the authors of this article recommend using an unambiguous phrase such as 'breaking bad news'.

TIME OUT 2

What are the main factors to consider when breaking bad news to a person with a learning disability? How would you decide what to tell them and how?

Experience of people with learning disabilities

McEvoy et al (2012) found that, among 34 adults with learning disabilities, most of them only had a partial understanding of the concept of death. In their systematic review, Lord et al (2017) found that the subjects of death, dying and bereavement are often surrounded by a culture of silence in learning disability settings. People with learning disabilities who are diagnosed with a life-limiting condition may not be aware that they are going to die; they will probably be told that they are ill, but they might not be given comprehensive information about their condition and prognosis (Tuffrey-Wijne et al 2020). Furthermore, people with learning disabilities are not always given the opportunity to make choices about important decisions regarding their health

and care (Tuffrey-Wijne et al 2018, Noorlandt et al 2020) and are less likely to be asked about their preferences for end of life care compared with the general population (Hunt et al 2020).

As with the general population, people with learning disabilities are more likely to be told that they may die if they have cancer than if they have another life-limiting condition (Tuffrey-Wijne et al 2020). Some people may find the practical consequences of a life-limiting diagnosis, such as frequent hospital visits or being too ill to enjoy their usual activities, more challenging rather than the diagnosis itself (Tuffrey-Wijne and Watchman 2015). Unexpected death is more common among people with learning disabilities than in the general population (Hunt et al 2020, Todd et al 2020), so there is often less time for the person and their family, friends and carers to plan for the end of life and it is less likely that the person will be able to die in their place of residence – whether that is in the family home or in a residential care setting (Todd et al 2020).

Brownrigg (2018) noted a tendency not to disclose bad news to people with learning disabilities in relation to their own health and prognosis and those of people important to them. Furthermore, people with learning disabilities are less likely to be informed of the death of a family member or friend (Tuffrey-Wijne et al 2020), or to be involved in funerals or other rituals with death and dying (McRitchie et al 2014).

TIME OUT 3

Reflect on your beliefs, attitudes and values about breaking bad news. How might these affect how you approach the subjects of death and dying with a person with a learning disability?

Barriers to breaking bad news

Cognitive and communication issues

The challenges in breaking bad news to people with learning disabilities can be compounded by cognitive and communication issues, notably if the person has a severe learning disability. The National Institute for Health and Care Excellence (2021) recommends that everyone should be involved in decisions about their care, but the extent to which people with learning disabilities are included in the decision-making process at the end of life depends on their ability (capacity) to make an informed choice (Noorlandt et al 2020).

Prognostic uncertainty often makes conversations about death and dying challenging (Anderson et al 2020) and this difficulty is compounded if the person with a learning disability struggles to understand the difference between past, present and future. Tuffrey-Wijne and Watchman (2015) suggested that, if the person does not understand the concepts of past and future, it may be best to focus on providing information about the present.

Some people with learning disabilities will have issues processing and retaining information, including about their health (Oosterveld-Vlug et al 2021). It is important to understand the person's existing knowledge base, since they may have limited life experience and knowledge gaps. Breaking bad news can be particularly challenging if the person also has dementia, since their knowledge base will decline over time as a result of the cognitive effects of their condition (Tuffrey-Wijne and Watchman 2015).

Attitudes of practitioners, families and carers

There are often several people involved in the care of a person with a learning disability and these people may have differing views about breaking bad news, potentially leading to disagreements. Families may be concerned that the person will find the bad news too distressing, be unable to cope or lack resilience. They may want to hear the news first to decide what to tell the person. Conversely, practitioners are more likely to want the person to

Key points

- Breaking bad news in the healthcare context may involve explaining to someone that they have a life-limiting condition or informing them of another person's illness or death, for example
- In learning disability settings, breaking bad news is often complicated by legal and ethical issues about mental capacity and by a desire to protect the person from distress
- Potential barriers with breaking bad news to people with learning disabilities include: cognitive and communication issues; attitudes of practitioners, families and carers; and environmental factors
- Tuffrey-Wijne's (2012, 2013) model for breaking bad news to people with learning disabilities has four main elements: building a foundation of knowledge; considering understanding and mental capacity; considering the people involved; and identifying the support people need

Online archive
For related information, visit **learningdisability practice.com** and search using the keywords

be informed as part of routine practice (Tuffrey-Wijne et al 2013). Not giving the person comprehensive information about their health could affect their treatment decisions, with potentially serious consequences (Tuffrey-Wijne et al 2010, 2020). For example, the person may decide not to proceed with life-saving or life-prolonging treatment because they have not understood the severity of their condition.

Practitioners, families and carers who decide not to disclose potentially distressing information to a person with a learning disability may think they are making that decision on compassionate grounds, or use this argument to justify their decision (Tuffrey-Wijne et al 2013). However, people's willingness to talk about death and dying is potentially affected by their attitudes, experiences, culture, beliefs and values (Tuffrey-Wijne and Rose 2017). Families and carers may be reluctant to break bad news to a person with a learning disability because it is emotionally challenging for them and/or because they lack medical knowledge (Tuffrey-Wijne et al 2013), while practitioners may lack knowledge about how to communicate with people with learning disabilities. This lack of knowledge may partly explain why, in contrast with the general population, people with learning disabilities tend to hear bad news from their family or carers, rather than from healthcare professionals (McEnhill 2008).

If the person with a learning disability struggles to understand what death means, practitioners, families and carers may feel less confident in talking to them about it (Gallagher et al 2018). If they are unsure how to best communicate with the person and/or how to manage consent and mental capacity issues, they might avoid the topic altogether (Kirkendall et al 2017).

The use of medical terms or complicated language is another barrier to people with learning disabilities understanding the information they are given, so practitioners need to use plain, simple language. Furthermore, it is important that practitioners ensure they make decisions based on what the person wants – as far as this can be determined – rather than what they think is right for the person (Gallagher et al 2018).

Environmental factors

Barriers to breaking bad news to people with learning disabilities include environmental factors that compound the person's difficulties in processing information, such as unfamiliarity with the surroundings, issues with the physical environment (for example suboptimal lighting, noise or a lack of privacy) and a lack of reasonable adjustments (Northway and Hopes 2022). Breaking bad news over the phone has increasingly occurred due to the coronavirus disease 2019 (COVID-19) pandemic (Collini et al 2021), but that mode of delivery may hinder the person's ability to process the news and increase their feelings of helplessness (Krieger et al 2022). It may also be inaccessible for people who rely on visual, technology-assisted or augmentative communication methods.

TIME OUT 4

Read about the SPIKES and BREAKS protocols at: **www.osmosis.org/blog/2021/03/15/breaking-bad-news-using-the-spikes-protocol-vs-the-breaks-protocol** What aspects of these tools would be useful in your practice?

Communication tools for breaking bad news

A growing number of tools, protocols and models are available that practitioners can draw on to break bad news to people, some of which are specific to the learning disability field. Generic tools can provide a useful general knowledge base but will often need to be supplemented with a specific tool.

Table 1 provides an overview of three generic tools for breaking bad news: the REDMAP framework (Boyd 2020), the

SPIKES protocol (Baile et al 2000) and the BREAKS protocol (Narayanan et al 2010).

ADVANCE toolkit

The ADVANCE toolkit (Gallagher et al 2018) has been specifically designed to support young people with learning disabilities and their families to plan end of life care. It is a values-based toolkit covering the following areas:

- Assumptions – avoiding making assumptions about the wishes of individuals and their families.
- Dignity – respecting diversity and maintaining dignity.
- Vulnerability – being sensitive to the person's vulnerability towards the end of life.
- Autonomy – maximising autonomy in decision-making and advocating on behalf of the person where needed.
- Non-discriminatory practice – respecting the person's rights and being open to different perspectives.
- Commitment – committing to provide ongoing, high-quality care and support.
- Environment of care – providing a safe, peaceful and private environment, as well as adequate time.

TIME OUT 5

Discuss with a colleague what you think effective practice would involve in terms of collaborating with families, carers and the wider support network of a person with a learning disability when breaking bad news

Tuffrey-Wijne's model

Irene Tuffrey-Wijne, a prominent researcher and advocate in the learning disability field, proposed an evidence-based model for breaking bad news designed specifically for people with learning disabilities (Tuffrey-Wijne 2012, 2013). Practitioners can adapt this model to different situations and break bad news in a way that is systematic and tailored to the individual. Tuffrey-Wijne's (2012, 2013) model involves four main elements:

- Building a foundation of knowledge.
- Considering understanding and mental capacity.
- Considering the people involved.
- Identifying the support people need.

Building a foundation of knowledge

When working with a person with a learning disability, practitioners need to use every opportunity to develop their

Table 1. Generic tools for breaking bad news

	REDMAP framework (Boyd 2020)	SPIKES protocol (Baile et al 2000)	BREAKS protocol (Narayanan et al 2010)
Description	A six-step guide to conversations on future care planning with people whose health is deteriorating and their families	Six-step mnemonics for conducting conversations about death and dying, originally developed for people diagnosed with cancer and now used more widely	
Steps	» **R**eady – checking with the person that they are ready to talk about their health and care, and asking who they would like to be involved in the conversation » **E**xpect – determining what the person expects from the conversation, what they already know and what they would like to say or ask » **D**iagnosis – discussing what is known, what is not known and what is uncertain, as well as eliciting the person's hopes and concerns » **M**atters – prompting the person to express what is important to them and their family, including how they would like to be cared for » **A**ctions – explaining the available options for what happens next and discussing what may or may not be helpful and why » **P**lan – make plans for future care, notably for if the person loses the mental capacity to make decisions	» **S** – setting up the interview » **P** – assessing the patient's perception » **I** – obtaining the patient's invitation » **K** – giving knowledge and information to the patient » **E** – addressing the patient's emotions with empathic responses » **S** – discussing a strategy for the future and summarising	» **B**ackground – understanding the person and their situation » **R**apport – establishing a therapeutic relationship with the person » **E**xplore – exploring what the person already knows, their beliefs and coping skills » **A**nnounce – communicating the diagnosis to the person in straightforward terms if appropriate, recognising that some people may not wish to hear the news and that this is a valid coping strategy » **K**indle – giving the person adequate space and time to express their emotions » **S**ummarise – summarising the session, future care plan and support

knowledge of that person and support them to develop their own knowledge about their health. This involves identifying how the person communicates, giving them opportunities to make choices and ensuring they have a range of experiences – for example arranging a visit to the hospital ward before an admission (Tuffrey-Wijne 2012, 2013).

Developing a therapeutic relationship with the person and their family is fundamental, since it gives people the language and opportunity to have an ongoing conversation with practitioners about what is important to them. Building a foundation of knowledge can be a slow process, so bad news cannot always be shared in a single conversation and breaking bad news should be seen as a process, rather than a single event. The therapeutic relationship is sustained by making time for people, being approachable, being reliable and giving consistent information (Wright 2021).

It is important to use concrete language and avoid the use of medical terms or euphemisms. Practitioners also need to be mindful of their tone of voice (Barber 2016, Ali 2017) and demonstrate sensitivity and compassion. Repeating information, breaking it down and relating it to the person's experience can support them to develop knowledge and understanding over time. Tuffrey Wijne (2012, 2013) described the process of identifying 'chunks' of knowledge that the person needs and delivering them over time and in a planned way, so that the person's knowledge base can be developed gradually. Chunks of information on 'what is happening right now' may be the easiest to understand at first and can later be complemented with chunks of information about 'what will happen in the future', if the person wants to know and is able to understand this (Tuffrey-Wijne 2012, 2013, Tuffrey-Wijne and Watchman 2015). Explaining to the person what is likely to remain the same between 'right now' and 'the future' can reassure them.

People with learning disabilities may find it easier to communicate through means other than verbally and it may be necessary to use images, photos, objects or places of reference of which the person has concrete experience and that mean something to them. Information can also be conveyed using a visual tool such as Talking Mats (Cameron and Matthews 2017). In some cases, practitioners may need to recognise that the person will not gain a full understanding of what the bad news may mean for them, but that should not stop them from broaching the subject with the person as best they can (McEnhill 2008).

Considering understanding and mental capacity

Each person will have their own preferences about how and to what extent they want to receive bad news (Tuffrey-Wijne et al 2013) and these preferences may change, so they need to be determined at every encounter. When given bad news, people with learning disabilities need to receive concrete and unambiguous information that is easy to understand (Tuffrey-Wijne et al 2013). The person's understanding of the information given to them will be crucial for how they cope and how they can be supported to plan for their future care, if they choose to do so.

Not disclosing bad news may be appropriate at one point in time, but this needs to be reassessed regularly and the person needs to be supported to express their preferences whenever their circumstances change (Tuffrey-Wijne et al 2013). Practitioners must follow the principles of the Mental Capacity Act 2005, including evaluating the person's mental capacity to make decisions about their care at every encounter.

Considering the people involved

It is often families, carers or residential care staff who break bad news to people with learning disabilities. However, these groups are often inadequately prepared for this task and insufficient consideration is

given to how the bad news may affect them and what support needs they might have (McEnhill 2008, Tuffrey-Wijne et al 2013).

Death and dying are relatively uncommon in learning disability settings, so staff may lack experience of such situations, possibly leading to more complex bereavement for them (Todd et al 2020). Tuffrey-Wijne and Rose (2017) highlighted challenges for staff who have known a person for many years when that person dies. It is important that practitioners who do not regularly work with a person with a learning disability enlist the assistance of people who know the person well (Lewis et al 2017, Gallagher et al 2018). Family carers often know the person best and are likely to be able to assist by sharing information about how the person communicates and how to communicate with the person (Gallagher et al 2018).

Tuffrey-Wijne (2012, 2013) explained the importance of considering who should break bad news to a person with a learning disability. If it is a medical matter, a nurse or doctor may be optimally placed to do so, with assistance from a family member or carer to ensure the news is shared in a person-centred way. However, even if it is a nurse or doctor who breaks the bad news, families and carers will support the person to understand and cope with it, so may need support with this and their own feelings about the situation (Tuffrey-Wijne et al 2013). Rauf and Bashir (2021) emphasised the importance of involving palliative care specialists and other members of the multidisciplinary team as well as families and carers when providing palliative care to a person with a learning disability.

Identifying the support people need

Whatever the extent to which a person with a learning disability understands what is happening to them, they will need support to cope with their changing circumstances. Finding out how the person has coped with challenges in the past is important. People with learning disabilities may use a range of coping strategies when experiencing stress (Burns and Lampraki 2016). Active coping – which involves problem-solving, finding information and seeking support – can reduce their psychological distress (Hartley and MacLean 2005, Goswami and Mohapatra 2016), while some people may be able to access treatments such as cognitive behavioural therapy (Giannaki and Hewitt 2021). Emotional support will be important and the person's spiritual needs may also need to be considered (Tuffrey-Wijne 2012).

Family and carers will also need support. Perera and Standen (2014) found that the coping strategies of families and carers looking after people with learning disabilities and dementia included solution-focused strategies, practical resources and obtaining support from others. Getting respite – ranging from a five-minute break to a weekend away – and creating a positive narrative about the person and their life also appear to be valuable strategies (Perera and Standen 2014). Practitioners can assist with developing a life story or photo album about the person and can encourage the family to take regular breaks and seek respite care.

The multidisciplinary team, family, carers and residential care staff need to work collaboratively to identify what each person's role will be. If a family member is the person who is going to break the bad news, healthcare professionals will need to support them in doing so. A named contact person responsible for communication between the family and services will be essential (Michael 2008, Bishop et al 2015, Gallagher et al 2018).

Practitioners themselves will also have support needs. Continuous reflection on practice will increase their self-awareness, knowledge and insights (Anderson 2019). Clinical supervision and support from colleagues and managers are crucial in encouraging practitioners to undertake self-care and be self-compassionate (Andrews et al 2020).

FURTHER RESOURCES

Irish Hospice Foundation – Toolkit for compassionate end-of-life care
hospicefoundation.ie/wp-content/uploads/2021/01/IHF-Toolkit-for-compassionate-end-of-life-care.pdf

Macmillan Cancer Care – Courageous conversations
www.macmillan.org.uk/dfsmedia/1a6f23537f7f4519bb0cf14c45b2a629/2187-10061

The Gold Standards Framework – Advance care planning
www.goldstandardsframework.org.uk/advance-care-planning

Conclusion

Breaking bad news is an important but challenging aspect of care provision. In learning disability settings, the task of breaking bad news can be compounded by several barriers. Various tools, protocols and models are available that can support practitioners to enhance their skills and confidence in breaking bad news. Each person is unique, so flexibility is required when applying any model in practice to ensure care is person-centred. It is also important that practitioners reflect on their practice and take time for self-care.

TIME OUT 6

Identify how breaking bad news to people with learning disabilities applies to your practice and the requirements of your regulatory body

TIME OUT 7

Now that you have completed the article, reflect on your practice in this area and consider writing a reflective account: **rcni.com/reflective-account**

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Test your knowledge by completing this multiple-choice quiz

Breaking bad news

1. 'Bad news' has been defined as:

a) An event or information of sufficient interest to the public to warrant press attention or coverage ☐
b) A report on a significant event with global consequences ☐
c) All information about socio-political events ☐
d) Any information that adversely and seriously affects an individual's view of their future ☐

2. Factors that can complicate breaking bad news in learning disability settings include:

a) Legal and ethical issues about mental capacity ☐
b) A desire to protect the person from distress ☐
c) A culture of silence about death and bereavement ☐
d) All of the above ☐

3. Which statement is false?

a) People with learning disabilities are less likely to be told they may die of cancer than other conditions ☐
b) People with learning disabilities who have a life-limiting condition may not know they are going to die ☐
c) Unexpected death is more common among people with learning disabilities than in the general population ☐
d) People with learning disabilities are less likely to be informed of the death of a family member or friend ☐

4. Which of these does not make breaking bad news to people with learning disabilities harder?

a) Prognostic certainty ☐
b) Cognitive and communication issues ☐
c) Difficulties understanding past, present and future ☐
d) Difficulties processing and retaining information, including about one's health ☐

5. Which statement is true?

a) Healthcare professionals are less likely than families to want someone with a learning disability to be informed of their diagnosis of a life-limiting condition ☐
b) People with learning disabilities tend to hear bad news about health from healthcare professionals rather than families or carers ☐
c) Families may be concerned that people with learning disabilities find bad news distressing ☐
d) Healthcare professionals should base their decisions about end of life care solely on what they think is right ☐

6. Which of these is an environmental barrier to breaking bad news to people with learning disabilities?

a) Unfamiliarity with surroundings ☐
b) Issues with lighting, noise and/or lack of privacy ☐
c) A lack of reasonable adjustments ☐
d) All of the above ☐

7. In the ADVANCE toolkit, what does the D stand for?

a) Death and dying ☐
b) Dignity ☐
c) Discuss ☐
d) Diagnosis ☐

8. Which of the following is not an element of Tuffrey-Wijne's model for breaking bad news?

a) Considering the people involved ☐
b) Considering understanding and mental capacity ☐
c) Considering the cause of the person's learning disability ☐
d) Identifying the support people need ☐

9. In Tuffrey-Wijne's model what does 'building a foundation of knowledge' entail?

a) Checking the person's preferences ☐
b) Supporting people to learn about their health ☐
c) Improving nursing students' knowledge of end of life care ☐
d) Consulting everyone involved in a person's care to decide who should break bad news to them ☐

10. When breaking bad news to a person with a learning disability, practitioners should avoid:

a) Using medical terms ☐
b) Showing sensitivity and compassion ☐
c) Repeating information ☐
d) Explaining what will remain the same in the future ☐

How to complete this assessment

This multiple-choice quiz will help you test your knowledge. It comprises ten multiple choice questions broadly linked to the previous article. There is one correct answer to each question.

You can read the article before answering the questions or attempt the questions first, then read the article and see if you would answer them differently.

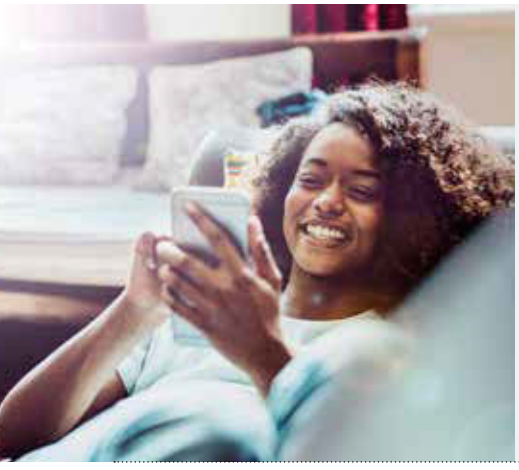
You may want to write a reflective account. Find out how at rcni.com/reflective-account

You can go online to complete this multiple-choice quiz at **rcni.com/cpd/test-your-knowledge** and save it to your RCNi portfolio to help meet your revalidation requirements

This multiple-choice quiz was compiled by Anne-Claire Bouzanne

The answers to this quiz are:

1. d 2. d 3. a 4. a 5. c 6. d 7. b 8. c 9. b 10. a



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After you have completed the process, please confirm your submission by email to **helen.hyland@rcni.com**

Article format and length

Articles should be submitted as a Microsoft Word or similar word-processing application document.

Text styling should be kept to a minimum, and text should be double-spaced with single returns to denote the ends of paragraphs.

Clinical articles should be between 3,000 and 4,800 words, including an abstract of 150 words maximum; body text; boxes, tables and figures if used; and references. Articles exceeding the word count will be returned to authors for cutting before peer review. For suggested word lengths of other articles, contact the editor.

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All articles must include references to original rather than secondary sources.

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