



Factsheet 9: Communication between care and support staff and people with learning disabilities and their families, including the use of hospital passports and communication books

Key considerations for reviewers

- Was there evidence of good communication between staff providing support and healthcare, the person with learning disabilities and their family?
- Where necessary, was the person communicated with in alternative ways, specific to their needs, to enable person centred care?
- Was accessible information made available where necessary?
- Did the person have a hospital passport or communication book?
- Did staff relate well to family and friends who knew the person best, welcoming their input and sharing information with them appropriately?

Introduction

Communication is central to providing person centred care (see Factsheet 10). In their review of learning disability services, the CQC (2012) found care was frequently not centred on the individual or tailored to their needs. Issues included care plans not being shared with the person, information not being provided in an accessible format for the person, and a lack of training in communication methods.

When caring for people with learning disabilities, professionals may need to adapt the way they communicate so that effective two-way communication can take place. They should also have personalised agreements about information sharing which take account of the capacity and views of the person with learning disabilities.

Supporting effective communication

There are some key things that can help support effective communication with people with learning disabilities:

- Involve the person as much as possible in their care, using alternative forms of communication specific to the person's needs where necessary.
- Know which decisions the person has capacity to make for themselves, which – if any - are to be made in their best interests (and by whom), which decisions they like to be supported with (how and by whom) and how they can be involved in decision-making even where they lack capacity.
- Give the person and their family (or paid supporter) information in advance to prepare them for a consultation.
- Talk directly to the person, involving the family (or paid supporter) with the person's permission when necessary.



- Ask family and others who know the person well for advice e.g. to find out about the person and what is important when communicating with them (e.g. do they use any of the aids mentioned below?)
- Find a place and time that suits the person and allow sufficient time for consultations.
- Build rapport with the person.
- Pay attention to body language and facial expressions to help communication with the person.
- Use alternatives to verbal communication if appropriate, such as gestures, facial expressions, pictures, photos or objects.
- Check what you have understood with the person, and possibly others who know them well.

Specific communication methods

Intensive interaction - Intensive interaction is a method of communication developed by Phoebe Caldwell that uses body language to encourage emotional engagement. It can help to build rapport and trust in relationships and help people to be more involved in their care.

Makaton – Makaton is an established communication tool that uses signs, symbols and speech to help people with learning disabilities communicate.

Easy read information - Presenting text in an accessible format known as 'easy read' can be helpful for people with learning disabilities, particularly with understanding often complex language used in health and social care. Making information 'easy read' involves breaking text down into short sentences, using images to represent each sentence of text, simplifying language and using large font sizes.

Books beyond words – for people who find pictures easier to understand than words or written material. All of the books tell a story in pictures, and allow the reader to tell their own story based on what they perceive in the pictures.

Talking mats - an interactive resource that uses picture communication symbols and a space on which to display them.

Communication tools

A **hospital passport** provides information that is useful for health and care staff to provide personalised care. It is a short document that outlines important information about a person and may include:

- Details about the person, their key contacts and services/professionals involved in their care
- How best to communicate with the person and what their support needs are
- What to do if the person becomes anxious and how to know if they are in pain
- Details of things that are important to the person
- Details of medication, allergies, risk of choking and how best to undertake medical interventions such as taking blood for that person
- How the person eats, drinks, sleeps and uses the toilet
- The sorts of decisions the person makes for themselves, how to support this and, if they lack capacity, who and how to contact people for Best Interest processes (e.g. Is there a Deputy? Which family member knows them best?)

A hospital passport should be taken with the person when they attend a healthcare appointment or change their care setting.



A **communication book** provides information and practical tools for communicating with people with learning disabilities, and may incorporate images, symbols, and photos that can be used to explain what is happening, what makes the person anxious, how to offer choices and help people with learning disabilities communicate to health and social care staff. Communication books may include:

- Information about key communication issues for people with learning disabilities, such as:
 - Supporting people with visual impairments or hearing loss
 - Using signing such as Makaton
 - Using photos, pictures and symbols
- Practical tools to help people with learning disabilities and health and social care staff communicate with each other including:
 - A set of pictures, symbols and photos to help with communication representing things like drinks, places, people and body parts
 - Pain charts
- Photographs or picture stories to explain an issue, procedure or health condition

A **pain assessment tool** helps to identify distress cues in people who have severely limited communication, which may indicate that they are in pain. It documents a person's usual behaviour, providing a record against which subtle changes can be compared. See factsheet 26 for more information.

Communication with families

- Family carers (i.e. siblings, cousins, aunts, uncles, grandparents and close friends as well as parents) should be respected, involved and treated as experts in care.
- Unless proven inappropriate, the Mental Capacity Act (2005) Code of Practice expects close family will be consulted over Best Interests decisions.
- The Care Act (2014) gives parity of esteem to carers. Under the Act local authorities have duties to prevent carers developing needs, to meet carers' eligible needs, to provide information and advice to carers, to shape the care and support market in response to needs (including those of carers). Assessments and planning should take a whole family approach, enabling carers to contribute to personalised care and support planning as well as their own support plans.
- The NHS Constitution (2015) says that NHS services "must reflect, and should be coordinated around and tailored to, the needs and preferences of patients, their families and their carers"; it pledges "to ensure those involved in your care and treatment have access to your health information so they can care for you safely and effectively" and states that staff should "be open with patients, their families, carers or representatives, including if anything goes wrong; welcoming and listening to feedback and addressing concerns promptly and in a spirit of co-operation."
- A CQC review of how NHS trusts investigate and learn from deaths, announced in April 2016, will investigate how well they support and engage with families of people who have died under their care (wherever they were at the time of death).

Speaking with a person's relative/s will enable you to find out if they were enabled to play their part in developing and delivering good support for them and what, if any, lessons can be learnt from their experiences.



Conversations with family and close friends

Respecting relatives involves being sensitive to language and communication style, just as with people who have learning disabilities. Your conversations will be most productive if you:

- **Prepare well:** agree a place (where the person can talk even if they feel distressed) and time that suit the person; have extra material about the LeDeR programme plus up-to-date details of local carer support and bereavement services should anyone require them; know how you intend to introduce yourself and explain what will be happening; consider any specific sensory or language needs of the family member.
- **Build rapport:** be friendly and clear about the purpose of your conversation, begin with fact-based questions, move onto open questions that encourage the person to say as much as they want to, adjust your pace and language to suit the person, listen carefully showing you are interested – clarifying what you have understood if necessary, let them know that what they share with you is valued and useful through being empathetic and supportive.
- **Answer questions** as fully as you can but if you cannot, say why this is.
- **Expect and make it alright for them to show difficult emotions:** grief, anger, frustration, sadness may make you feel anxious and wonder what you can do to help but allowing and quietly acknowledging these feelings without trying to take charge will make it easier for the person to say what they want to say. Being listened to in a non-judgemental, but interested, way helps most people, especially when they know others want to learn from their views and experiences.
- **Ending:** reverting to factual information (e.g. what will happen next, how the person can be kept informed about LeDeR, when reports will be available) can help bring an emotional conversation back to a more neutral grounding. It may also be helpful to ask about something beyond the situation, such as the journey home or plans for later in the day.

Additional sources of information

Resources for communicating with people with learning disabilities:

- Jargon buster https://www.gmc-uk.org/learningdisabilities/Jargon_Buster_A4_chart.pdf_47935778.pdf
- Books beyond words <http://booksbeyondwords.co.uk/>
- Easy read <http://www.easyonthei.nhs.uk/accessible-information-standard-what-is-easy-read>
- Intensive interaction <http://www.phoebecaldwell.co.uk/work.asp>
- Makaton <https://www.makaton.org/aboutMakaton/>
- Talking mats <http://www.talkingmats.com/about-talking-mats/>
- Disability Distress Assessment Tool: <http://www.stoswaldsuk.org/how-we-help/we-educate/resources/disdat.aspx>

Royal College of Speech and Language Therapists 'Five good communication standards: Reasonable adjustments to communication that individuals with learning disability and/or autism should expect in specialist hospital and residential settings' http://www.rcslt.org/news/docs/good_comm_standards

Hospital Communication Book

http://www.easyhealth.org.uk/sites/default/files/hospital_book_section%201.pdf

Hospital Passport [http://www.easyhealth.org.uk/listing/hospital-passports-\(leaflets\)](http://www.easyhealth.org.uk/listing/hospital-passports-(leaflets))