

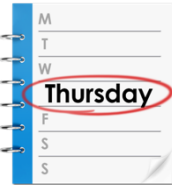



## Family Carers Briefing Communication, March 2018

	<p>Our Family Advisers have been talking to family carers of adults with a learning disability, autism or both to find out what issues they are facing. From speaking and meeting with carers and feedback in the recent survey they have written short guides based on the key issues which came up. We hope you find these useful.</p>
  	<p>3 out of every 4 (75%) of the people who took part in the survey and many carers who we met said communication <u>with</u> carers and <u>between</u> different services was a problem. Poor communication was frustrating and often made difficult situations worse. Problems included:</p> <ul style="list-style-type: none"> <li>• Appointment dates being sent out at short notice.</li> <li>• Organisations ignoring how carers' want to be contacted, whether that's email, letter or telephone.</li> <li>• Carers feeling frustrated at having to “tell their story” over and over again to different service providers. Having to repeat things that have not changed (about someone's early life or diagnosis, for example) does not make carers feel respected.</li> </ul>



- Having to repeat information feels like it is wasting time in appointments which could be better spent getting help, advice and support.



**Positive practice:**

Where carers had seen good communication, they said it was:

**Clear** - for example about what would happen next after a consultation or meeting.

**Flexible** - with information sent in writing but followed-up with a phone call to check understanding.

**Thorough** – professionals making sure carers had copies of the reports they produced.

**Informed** – the best professionals were willing to apply their professional skills to helping family carers by offering advice and being willing to put that in writing. They also made sure their knowledge of the cared-for person was up-to-date.

**Kind and respectful** – the best and most useful communication came from an attitude of kindness and mutual respect, and an acknowledgement that the carers and professionals were a team, working together.

Carers often have to know a lot about health services to support the person they care for, and to do that they need access to good information. NHS England are producing more of their publications in both standard and easy-read formats, making them



more accessible. Here is a link to all NHS England's publications <https://www.england.nhs.uk/publication/>

The Accessible Information Standard says that people who have a disability or sensory loss should get information in a way they can access and understand. All NHS and Adult Social Care organisations have to meet this standard. There is more about the standard, including Easy Read information, on the Standard's website. For more information go to:

<https://www.england.nhs.uk/publication/accessible-information-standard-overview-20172018/>

Some carers have found it useful to produce a one page history of the person they care for, so that they don't have to keep repeating their story. Leeds Mental Health Teaching NHS Trust has produced an Accessible Health Record. It takes a while to complete for the first time, but then the information is there whenever it's needed. For information go to:

<http://www.easyhealth.org.uk/sites/default/files/My%20health%20record.pdf>

Rotherham Doncaster and South Humber NHS Foundation Trust have produced a Traffic Light Assessment Tool that helps people with disabilities and their carers provide hospital staff with important information on the individual's condition and preferences before a hospital stay, so that staff aren't relying just on communication from the patient and their carers. Please see:

<https://www.rdash.nhs.uk/25288/traffic-light-assessment-tool/>

Dimensions is a charity which supports people with learning disabilities and autism to have a voice,

choice and control in their lives. They have Family Consultants to support clear communication with family carers. Their National Family and Friends Forum is an important part of their governance structure. Members meet regularly to make sure concerns or suggestions are dealt with at Board level and that families' views are heard in important decisions. Dimensions' charter, covering communication and family carer involvement, may be useful. Go to: <https://www.dimensions-uk.org/families/family-involvement/>



### Resources:

In 2013, Skills for Care published a Code of Conduct for Healthcare Support Workers and Adult Social Care Workers in England. It has a section on communication and says that support workers should “**communicate in an open, and effective way to promote the health, safety and wellbeing of people who use health and care services and their carers**”. To view the full document go to:

<https://www.skillsforcare.org.uk/Document-library/Standards/National-minimum-training-standard-and-code/CodeofConduct.pdf>



The Social Care Institute for Excellence has published a series of training modules, including some available online. This includes training for staff on good communication. Please see:

<https://www.scie.org.uk/training/>

The Tech4Goodawards are for innovations to support people with disabilities. Several of the past winners have made interesting use of new technology to improve communication for people with disabilities. More details of the winners are on the website: <https://www.tech4goodawards.com/>

### **Additional information:**

NHS organisations have guidance on how they store, use and share information about individuals. The guidance also applies to adult social care where care is provided jointly with the NHS. Sharing information is both **allowed and encouraged** where it will support better care. See:

<https://www.gov.uk/government/publications/records-management-code-of-practice-for-health-and-social-care>



Service providers are starting to use email and text messaging to contact both carers and people with disabilities. Carers said this can be useful when it is basic information or urgent notifications, such as last-minute changes to appointments, but several carers felt that longer or more complicated communications should be by letter (or email if the carer had asked for communication to be that way).

It is important that carers tell services how they want to get information, whether that's by post, email or telephone.