

One Size Does Not Fit All: Obtaining informed consent from people with aphasia



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Obtaining informed consent is difficult when an individual has a communication disability, presenting challenges when involving patients in decisions about their medical treatment, giving power of attorney, participation in research and in discharge planning. There is a growing awareness that people with aphasia can give informed consent if information is provided in an accessible format. However, the range of language disability that can be experienced makes it unlikely that one approach will facilitate understanding of all people with aphasia. In an NIHR Research for Patient Benefit (RfPB) funded project, the authors are piloting a procedure to differentiate methods of making information accessible according to aphasia severity.

Respect for the right of individuals to be fully involved in decisions about their healthcare is laid out in The NHS Constitution (2010).¹ One of the key principles is that "NHS services must reflect the needs and preferences of patients, their families and their carers." In addition it commits to making "decisions in a clear and transparent way, so that patients and the public can understand how services are planned and delivered". These rights are also reflected in The World Medical Association Declaration of Helsinki which sets out the ethical principles that guide medical research.²

Health professionals are aware that a patient must have decision-making capacity as a prerequisite for providing informed consent.³ The Mental Capacity Act (2005) details the abilities that demonstrate capacity to make an informed decision: a) to understand the information relevant to the decision; b) to retain that information; c) to use or weigh that information as part of the process of making the decision; and d) to communicate the decision (whether by talking, using sign language or by any other means).⁴ For people with aphasia, difficulty in communicating a decision verbally or through writing is clear to most professionals who are trying to establish their wishes. More important (but often less obvious) is the fact that the person with aphasia may not have understood the written information or a verbal explanation of the issues to be considered. The Mental Capacity Act states that people should be given the opportunity to make their own decisions as far as possible stating that "A person is not to be regarded as unable to understand the information relevant to a decision if he is able to understand an explanation of it given to him in a way that is appropriate to his circumstances (using simple language, visual aids or any other means)".⁴

The Connect communication disability network has contributed greatly to the inclusion of people with aphasia in decision making by providing

advice on how to produce information that is accessible to people with compromised language skills.⁵ They advocate ideas for making written information easier to understand such as use of short sentences with key words emboldened, pictures to illustrate key ideas and space between each concept.

Such accessible formats are being used by a growing number of health professionals and researchers.^{6,8} However, it is important to emphasise that whilst protecting an individual's right to make autonomous decisions by providing information in a more accessible format using the standard conventions recommended by Connect above, some individuals with aphasia will still not possess the level of language ability required to understand the information in this format. For example, if they are unable to read at all, highlighting key written words will not help inform them. Therefore the authors propose that by acknowledging the existence of a communication disorder and applying a standard set of conventions for making information accessible, we cannot assume that we have adequately informed the specific individual we are interacting with. In order to provide information in a way that is consistent with the individual's level of language, it is necessary to be familiar with the profile and severity of their abilities. Although a full assessment of language is a complex process and requires skilled speech and language therapists, communication screening tests for other health professionals have been validated, for example the Frenchay Aphasia Screening Test⁹ and the Sheffield Screening Test for Acquired Language Disorders.¹⁰ These screening tests indicate the presence and severity of aphasia and so give an indication of the person's communication ability. The procedure being piloted in the RfPB funded project tailors the information giving process to the needs of the individual as follows:

The amount of spoken and written information the individual understands is established through a screening test. Expressive difficulties are determined along with strategies that help the individual to express themselves effectively. Provision of information is then matched to the level of language ability in the following way:

1. If written paragraphs are fully understood a written information sheet is provided using lay terminology with key ideas highlighted. (If written paragraphs are understood but it is time consuming or effortful for the individual, they are given the option of reading information using the standard aphasia friendly conventions)
2. Where the individual understands at least three

key words in a written sentence, e.g. 'Point to the floor, the ceiling and the window'. Information is provided using the full range of standard aphasia friendly conventions advocated by Connect: removing jargon and acronyms and using straight forward language; keeping one main idea per sentence; using active not passive sentences; using bullet points rather than blocks of text; using a question and answer format; using a plain, clear font in size 14 pt; use of plenty of white space; use of relevant and respectful pictures or diagrams to help get the message across and providing summaries of key points.

- Where the aphasia limits the individual to understanding only two key written or spoken words in a sentence, e.g. 'touch your head and your knee', the standard aphasia friendly format may be difficult to interpret without additional support. For these individuals a 'total communication approach' is used whereby each key idea is presented on a separate powerpoint slide using key written words and illustrations or animations. The visual presentation of the information is also supported by spoken explanations, drawing and gesture.
- Where aphasia is more severe and less than two key written or spoken words are understood, the authors suggest that it will be difficult to be sure that we have fully informed the individual of important concepts such as their right to withdraw without affecting future treatment, or concepts that are outside of the immediate environment such as implications of discharge choices. In this case simple pictures and key words, or a short video clip are used to inform the individual about the key topic area and to establish their general feelings about it. Fully informed consent is then sought from a

relative or carer who is given the complete information.

These different methods of providing information were approved by the Bradford ethics committee in advance of piloting them in the RfPB funded study.

Part of the consent process involves the individual asking questions to ensure full understanding of what is going to happen. When the ability to speak is compromised asking questions is difficult. The procedure being piloted encourages the individual to describe a situation if they can't find the right words, or to use gesture, point to pictures or draw. If their speech is difficult to understand, asking them to slow down or write key words can help. Stein et al recommend a process of facilitated consent whereby a person who knows the individual's history, values and preferences asks questions that the individual would ask if he/she could do this easily.³

Decision making capacity as defined by the Mental Capacity Act is specific to a particular decision being made at a specific time. Once information has been presented in a format that is most consistent with the individual's ability to understand written and spoken language, strategies can be used to ensure that the specific information has been understood before taking consent. These include presenting forced alternatives, e.g. 'Are we going to give you a tablet or a questionnaire?', 'If you want to stop, do you have to carry on, yes or no?'. For participants who have reduced understanding of spoken language, pictures can be provided to sort according to their relevance to the information given. Additionally, pictures can be given for the participant to sequence the order in which events will happen.

Where individuals with severe aphasia do not demonstrate understanding of the decisions to be made, or of their implications, the Mental Capacity Act states that a decision should be made in the individual's best

interest and that the decision should be the least restrictive of their basic rights and freedoms.⁴ People involved in caring for the individual who lacks capacity should be consulted and where there are no family members or close friends, an independent mental capacity advocate (IMCA) can be appointed to speak on the patient's behalf.

In summary, this article proposes ways of presenting information consistent with different severities of aphasia, strategies for checking information has been understood and ways to identify those who are unlikely to be able to provide informed consent. ♦

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