

RESEARCH BRIEF

Notifying and supporting people who have acquired a risk for Creutzfeldt-Jakob disease (CJD) as a result of medical treatment

This RESEARCH BRIEF has been prepared for the consumer group CJD Support Group Network by the Cochrane Consumers and Communication Review Group, an arm of the Centre for Health Communication and Participation at La Trobe University. It is a condensed version of a larger research report. This RESEARCH BRIEF was supported by a donation in memory of Mr. Allan Patrick Field.

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The full report is available on the Victorian Department of Health's website:
<http://www.health.vic.gov.au/doh/index.htm>

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This is a one-page synopsis of the research brief.

In 2006, the Cochrane Consumers and Communication Review Group (CC&CRG), part of the Cochrane Collaboration - a non-profit health research organisation - undertook a systematic review of the evidence on notification and support strategies for people at risk of medically-acquired Creutzfeldt-Jakob disease (CJD). The review was funded by the Public Health Division of the Victorian Department of Human Services.

Background

CJD is a rare and fatal neurological disease that can be transmitted through specific medical procedures. There is no screening test or effective treatment option for the disease and it can be passed between surgical patients despite instrument sterilisation.

To protect the public health, people must be informed when they may have been exposed to CJD risk because additional infection control measures may be needed for some medical procedures. With no way to test to see if an individual is incubating CJD, potentially infected individuals can be told only that they are at an increased risk of developing the disease. The seriousness of the disease and the uncertainty of the risk can make notification a highly distressing event. It may also lead to problems in the future such as discrimination in accessing health care.

For these reasons, communication related to CJD must be carefully considered. The information must be conveyed in a way that causes the least harm to individuals and their families.

Results & Recommendations

From the research, we developed a framework to inform how communication might best be carried out when people are exposed to the risk of CJD via medical treatment. The major theme of the framework is the need for a standardised, planned approach to notification and support.

Our recommendations can be broken down into four key areas:

National Communication Policy

There should be an overarching national standard for all communication related to CJD risk, so that when incidents occur people know what to do and how to respond.

Notification

Notification must be planned, deliberate and must consider the impact of the information. It must ensure that people receive the best possible care and that communication happens in a manner that causes the least anxiety and distress.

Support

People at risk need ongoing access to trained and knowledgeable support services, which must be able to respond to the changing needs of the at-risk community.

Education and Information

Many groups, including health professionals and the wider community, must be educated and informed about CJD and risk. This communication should also be standardised, because it may affect the wellbeing of individuals at risk in direct and indirect ways.

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Who We Are

The Cochrane Consumers and Communication Review Group (CC&CRG), an arm of the Centre for Health Communication and Participation, is part of the Cochrane Collaboration, an international non-profit organisation that aims to help people make well-informed decisions about health care. This is done by the preparation, maintenance and promotion of systematic reviews of the effects of healthcare interventions, published on *The Cochrane Library* (www.thecochranelibrary.com).

What is this research brief?

This research brief summarises the findings of a large research project. The type of research is called a systematic review. In 2006, the CC&CRG began a systematic review of the evidence on strategies for notifying and supporting people at risk of Creutzfeldt-Jakob disease (CJD) acquired through medical treatment. The report was funded by the Public Health Division of the Victorian Department of Human Services.

We searched widely to identify all relevant research. We located and assessed 41 pieces of research and literature, including documented accounts of people's views, preferences, and experiences. We included information from formal complaints. We also analysed policy and consensus documents and reports from legal or parliamentary enquiries.

The literature that we reviewed suggested that a planned, standardised approach to CJD risk communication was necessary to provide the best care for those at risk and their families. We developed a patient-centred communication framework outlining a broad range of strategies. This framework can be used as a tool—along with further research—by healthcare policy makers aiming to improve communication processes.

What is CJD and Who Does It Affect?

Classical Creutzfeldt-Jakob disease (CJD) and variant CJD (vCJD) are rare, fatal diseases with very long incubation periods. While classical CJD can occur spontaneously or genetically, this report focuses on those forms of CJD and vCJD that are acquired through medical procedures (iatrogenically).

CJD can be transmitted through a small number of specific medical procedures, such as brain surgery and the use of human pituitary hormone products. Variant CJD is acquired by consuming contaminated meat, and it can also be transmitted through blood transfusions. There is no screening test or effective treatment option for either CJD or vCJD. Both forms are resistant to routine sterilisation and can therefore, in rare cases, be passed between surgical patients, despite standard instrument sterilisation.

The Importance of Communication

To protect the public health, people must be informed when they may have been exposed to CJD risk and additional infection control measures may be needed for some selected medical procedures. However, there are several features unique to this disease that make communication very difficult. Because there is no screening test for CJD and it is resistant to medical sterilisation techniques, people undergoing certain types of surgery (eg brain, spine and posterior eye surgery) may be treated with potentially infected equipment. This happens in a very small number of cases, if they are operated on after the instruments have been used on a patient incubating CJD. The long incubation period means that the risk may not be identified until years or even decades later when an individual develops what is later confirmed to be CJD. At that point, the individual's medical history must be traced backwards and anyone who may have been exposed to the risk of infection must be notified. In some cases, hundreds of people may need to be contacted.

With no way to test for CJD or vCJD, potentially infected individuals can be told only that they are at an increased risk of developing the disease. The seriousness of the disease and the uncertainty of the risk can make notification a highly distressing event, which may cause significant anxiety and psychological harm. It may also lead to future problems such as discrimination in accessing health care.

For these reasons, communication related to CJD must be carefully considered. The information must be conveyed in a way that causes the least harm to individuals and their families.

Evidence-Based Communication

When a doctor reviews the available scientific studies regarding the effectiveness of a certain treatment before prescribing a drug or other treatment, he or she is practicing 'evidence-based medicine'. All evidence-based medicine decisions are based on scientific research, which is considered more reliable than an individual expert's opinion alone.

While this practice is fairly straightforward in the case of prescription drugs, for example, it can also apply to less concrete medical interventions, such as health communication. There is growing recognition of the role of effective communication and support in improving outcomes for consumers, and this is known as evidence-based communication. Evidence-based communication suggests that the form and manner in which a patient receives information from and interacts with the health care system can be beneficial or harmful, just like different prescription drugs. For instance, research has shown that computer-based interactive health communication applications provided for people with chronic disease may improve outcomes, such as increasing knowledge, increasing a sense of perceived social support and leading to better health.

Results & Recommendations

From the research, we developed a framework to inform how communication might best be carried out when people are exposed to the risk of CJD via medical treatment. The major theme of the communication framework is the need for a standardised, planned approach to notification and support, as opposed to ad hoc or disconnected communication events. Practically, this requires a series of coordinated, interrelated communication processes as well as appropriate support and educational structures for individuals at risk and groups including health care professionals, the public and the media. *(For an illustration of the communication framework proposed, please see the diagram at the end of this document.)*

The framework may be broken down into several sections, each involving a different set of responsibilities and involving different groups and individuals. The framework is fundamentally patient-centred, meaning that all decisions and actions should be flexible and responsive to the needs of the person at risk and his or her family.

National Communication Policy

Key Message:

There should be an overarching national standard for all communication related to CJD risk, so that when incidents occur people know what to do and how to respond.

Responsibilities and important elements of a national policy framework include:

- Establish a standardised process for notifying people that they may be at risk, including updating people whose at-risk status changes through further discoveries.
- Develop the framework through consensus meetings involving policy makers, representatives and members of professional colleges, healthcare workers, experts, and particularly consumers from CJD-affected groups.
- Protect the confidentiality of people at risk and monitor health care access to ensure no discrimination occurs.
- Recognise and respect the upsetting nature and uncertainty of the information and the need for an ongoing and supportive relationship with people at risk and their families
- Include a standardised process for how and when to inform, who informs, and what is said.
- Perform additional research, seeking feedback from people at risk to determine the long-term social and psychological effects of living with risk, and the best formats for risk notification.

Notification

Key Message:

Notification must be planned, deliberate and must consider the impact of the information. It must ensure that people receive the best possible care and that communication happens in a manner that causes the least anxiety and distress.

The four key elements to notification are:

- Notification should be standardised in form and timing, personalised, and clearly and concisely stated. It should acknowledge the uncertainty of risk and provide a rationale for the notification.
- The person delivering the information (in most cases, the individual's GP or other clinician) should be someone the individual knows, rather than an unfamiliar healthcare professional. The informant should be trained and knowledgeable about the disease, and should offer access to further information and support services.
- The individual's clinician must be educated and notified in advance, and should be available to provide information and ongoing support and consultations.
- Though the research into the best format for notification is not conclusive, it suggests that being told by telephone may be the method that people favour least. A letter or consultation, or a combination of these two, may be the preferred method.

Support

Key Message:

People at risk need ongoing access to trained and knowledgeable support services, which must be able to respond to the changing needs of the at-risk community.

Six important features of the support system are:

- Support networks, including consumer support groups and counselling services, must be in place and informed before any notification of individuals occurs. Whenever a new incident occurs, such as a new identification of risk or the death of an at-risk individual from CJD, the support system must be informed before people are notified, to ensure readiness to provide support.
- Because the needs of individuals are likely to change over time, support services must be available on a long-term basis and should be responsive to these changes, taking into account the effect of new discoveries and incidents upon the needs of individuals.
- Wherever possible, support should be tailored to the needs and desires of the individual. For instance, one person might want regular updates provided to them by newsletter, while another may wish to receive information only when he or she contacts the support group.
- All information provided should be understandable, easily accessible and accurate.

- Support staff must be trained appropriately, both in areas pertaining to CJD and in proper and effective communication and support techniques.
- Consumer groups should encourage individuals to report healthcare discrimination, and the information should be fed back to health departments and services.

Education and Information

Key Message:

Many groups must be educated and informed about CJD and risk. This communication should also be standardised, because it can affect the wellbeing of the individual in direct and indirect ways.

In addition to other communication efforts, coordinated education and information campaigns should include the following four groups:

- **Health professionals** must be educated about CJD, risk and infection control guidelines. They should be made aware of the communication protocols and the potential negative impact of poor notification strategies.
- **Consumer support groups** must be informed when incidents and developments occur. These groups in turn should raise awareness of their activities and functions, to enable those at risk to access support services.
- **Public** communication should include community education and referral to further information and support. Greater public understanding and awareness may reduce discrimination.
- Communication with the **media** should emphasise sensitivity to those at risk. When incidents occur, individuals should hear of them through the appropriate personalised channel rather than from a media outlet. Members of the media should be educated to avoid the perception that CJD is caused by medical negligence.

How Should This Report Be Used?

The communication framework and suggestions we have developed from our research are intended to be used as tools for health departments and public health agencies to standardise and improve their education and communication processes surrounding CJD risk.

We also recommend further research. We found significant gaps in the evidence, specifically regarding the ongoing social and emotional impacts of living with the risk of CJD, as well as the appropriate formats for presenting risk and uncertainty.

Figure 1: Major components of the framework for improving communication with people exposed to the risk of CJD via medical treatment

