

Guidance on Open Disclosure Policies

HDC wishes to promote a clear and consistent approach to open disclosure by health-care and disability services providers. It is what consumers want and are entitled to. Right 6 of the Code of Health and Disability Services Consumers' Rights gives all consumers the right to be fully informed (ie, to receive the information that a reasonable consumer in his or her situation would expect to receive). Consumers have a right to know what has happened to them.¹

The principles underpinning open disclosure were established over 25 years ago and remain constant: health-care providers should openly and honestly discuss adverse events that occur during health care that cause harm to patients.² Internationally, there is a move towards the development of national standards and organisational policies to promote open disclosure. In New Zealand, provider organisations have a legal duty to take steps to ensure that open disclosure is practised by staff and supported by management.

Set out below are guiding points that provider organisations should consider when developing open disclosure policies.

WHAT SHOULD OPEN DISCLOSURE INCLUDE?

- A consumer should be informed about any adverse event, ie, when the consumer has suffered any unintended harm while receiving health care or disability services.³
- An error that affected the consumer's care but does not appear to have caused harm may also need to be disclosed to the consumer. Notification of an error may be relevant to future care decisions — whether or not to go ahead with the same procedure on another occasion. The effects of an error may not be immediately apparent.
- A disclosure should include acknowledgement of the incident, an explanation of what happened, how it happened, why it happened and, where appropriate, what actions have been taken to prevent it happening again. (In some situations, specific actions will need to be taken straight away, whereas in other situations where the explanation is still unfolding, the actions that need to be taken may take longer to identify.)
- A disclosure should include a sincere apology.⁴ This is the provider's opportunity to say, "We are sorry this happened to you." It is not about allocating blame for

¹ Otolaryngologist Dr B and Southern District Health Board — A Report by the Health and Disability Commissioner, Case 16HDC01980. Available online at www.hdc.org.nz.

² R Harrison, M Walton, J Smith-Merry, E Manias, and R Iedema (2019), "Open disclosure of adverse events: exploring the implications of service and policy structures on practice". *Risk management and healthcare policy*, 12, 5–12. doi:10.2147/RMHP.S180359.

³ Massachusetts Coalition for the Prevention of Medical Errors, *When things go wrong: responding to adverse events* (2006) 4.

⁴ See NHS National Patient Safety Agency, *Being Open — Saying sorry when things go wrong*; London, November 2009. Available online at: <http://www.nrls.npsa.nhs.uk/resources/?entryid45=65077>.

the event's occurrence, but acknowledging the seriousness of an adverse event and the distress that it causes. Apologies can bring considerable comfort to the consumer and have the potential to assist with healing and resolution.⁵ In some situations, an apology may be critical to the consumer's decision about whether to lay a formal complaint and pursue the matter further.

- The consumer should be given contact details and information about the local health and disability consumer advocate, as well as options for making a complaint.⁶

WHY IS OPEN DISCLOSURE IMPORTANT?

- Because ethically and legally it is the right thing to do.⁷
- There are a number of rights under the Code of Health and Disability Services Consumers' Rights (the Code) that are relevant to open disclosure (see below).
- Open disclosure standards are included in the revised Health and Disability Services Standards that must be followed by all health and disability services providers certified under the Health and Disability Services (Safety) Act 2001.⁸
- Open disclosure:
 - affirms consumers' rights;
 - fosters open and honest professional relationships; and
 - enables systems to change to improve service quality and consumer safety.
- Because the physical harm from an adverse event is often compounded by an emotional or psychological harm when consumers discover that relevant information has been withheld from them.⁹
- Consumers want to know when things go wrong and why, and providers and provider organisations have a legal duty to promote the disclosure of such information in accordance with their individual or organisational duty of care.
- Consumers want to know what the consequences could be for them and their ongoing care. It is important to discuss how the event could change anticipated care and any effects the consumer may experience as a result.
- Consumers are also interested in any action taken as a result of the error or adverse event. Many are concerned that the same thing does not happen to anyone else, that changes are made to the relevant systems, and that staff learn from the experience.¹⁰

⁵ See D Frenkel and C Leibman, "Words that heal" (2004) 140 *Annals of Internal Medicine* 482; J Robbenolt, "Apologies and legal settlement: an empirical examination" [2003] *Michigan Law Review* 102.

⁶ The Nationwide Health and Disability Consumer Advocacy Service can be contacted by telephone on 0800 555 050, or by email at advocacy@advocacy.org.nz. Further information about the service can be found online at www.advocacy.org.nz.

⁷ See R Lamb, "Open disclosure: the only approach to medical error" (2004) 14 *Quality and Safety in Health Care* 3.

⁸ Ministry of Health, New Zealand Standard *Health and Disability Services Standards*, NZS 8134.:2008.

⁹ See C Vincent and A Coulter, "Patient safety: what about the patient?" (2002) *Quality and Safety in Healthcare* 11(1): 76–80.

¹⁰ M Bismark, E Dauer, R Paterson, and D Studdert, "Accountability sought by patients following adverse events from medical care: the New Zealand experience" (2006) 175 *CMAJ* 889; M Bismark and R Paterson, "'Doing the right thing' after an adverse event" (2005) 1219 *NZMJ* 55; A Witman, D Park,

- It also helps to ensure that consumers are advised that they may be entitled to compensation under ACC, so that appropriate forms can be completed in a timely manner.

WHO SHOULD BE INVOLVED IN THE DISCLOSURE?

- The individual provider with overall responsibility for the consumer's care should usually disclose the incident. Research suggests that consumers prefer to hear from a provider with whom they have built a rapport or had previous contact. Where this provider is not the provider with overall responsibility, both providers should be in attendance.¹¹
- Research suggests that disclosures by administrative staff or management alone are not well received, although in some cases, particularly where significant harm has resulted, it may be appropriate for senior management to attend with the individual providers involved.

WHEN/WHERE SHOULD THE DISCLOSURE TAKE PLACE?

- Disclosure should be made in a timely manner, usually within 24 hours of the event occurring, or of the harm or error being recognised.
- Although disclosure to the consumer concerned should not occur until he or she is medically stable enough to absorb the information and is in an appropriate setting, there is likely to be a suitable person (ie, someone who is interested in the welfare of the consumer and is available) who should be informed. This may include an enduring power of attorney or legal guardian.
- In the immediate aftermath of an adverse event, providers may be searching for answers too. In these circumstances it is appropriate to acknowledge the limits of what is known, and to make a commitment to sharing further information as it becomes available.¹²
- It is important to emphasise that open disclosure is not a single conversation, but a process of ongoing communication. Communication should continue until the consumer (and/or the consumer's representative or the suitable person who has been informed) has all the information and support needed.
- If the incident occurred in a team environment, it may be beneficial for the team to meet prior to the disclosure taking place. The Medical Council of New Zealand's guidelines for doctors suggest that the team meet to discuss:¹³
 - what happened
 - how it happened

and S Hardin, "How do patients want physicians to handle mistakes? A survey of internal medicine patients in an academic setting" (1996) 156 *Archives of Internal Medicine* 2565; M Higorai, T Wong, and G Vafidis, "Patients' and doctors' attitudes to amount of information given after unintended injury during treatment: cross-sectional, questionnaire survey" (1994) 318 *BMJ* 640.

¹¹ New Zealand Medical Council, *Disclosure of harm following an adverse event*, December 2010 (available at www.mcnz.org.nz).

¹² M Bismark and R Paterson, "'Doing the right thing' after an adverse event" (2005) 1219 *NZMJ* 55.

¹³ New Zealand Medical Council, *Disclosure of harm following an adverse event*, December 2010 (available at www.mcnz.org.nz).

- the consequences for the consumer, including arrangements for continuity of care
- what will be done to avoid similar occurrences in the future
- who should be present when the harm is disclosed to the consumer.
- It might not be possible, however, for the team to discuss the incident and any harm before a discussion with the consumer takes place. An opportunity for the team to debrief should not unreasonably delay the consumer's (or his or her representative's) receipt of information.
- It may be appropriate for an early initial disclosure to occur, followed by a more detailed discussion with the consumer once the team has had an opportunity to meet.

HOW SHOULD OPEN DISCLOSURE TAKE PLACE?

- Disclosures should generally be made to the individual consumer and any family/whānau/key support people the consumer wishes to have present.
- In some situations where the consumer has died, has been significantly compromised, has long-term diminished competence, or is incompetent, disclosure will need to be made to a third party.
- In circumstances where discussion with the consumer is not possible or appropriate, his or her representative, or a suitable person (who is interested in the welfare of the consumer and is available), such as the consumer's next of kin or designated contact person, should be informed.
- Consideration must be given to the consumer's cultural and ethnic identity and first language, and the support needed.
- Details about the incident and any harm, the disclosure, and any subsequent action should be fully documented in the consumer's records.
- It is important that health professionals and other personnel involved also have access to support. Numerous studies have shown that most errors are made by well-trained people who are trying to do their job, but are caught in a flawed system that predisposes towards mistakes being made.¹⁴
- Provider organisations need to take steps to ensure that the policy is applied in practice. Ongoing staff training on open disclosure needs to take place so that staff are able to respond promptly and confidently when things go wrong. All personnel, including providers with independent access agreements and relevant contractors such as relief providers, also need to be aware of the policy, and adequately trained and supported in its implementation.
- Training in communication is especially important.¹⁵ An adverse event or incident is emotionally charged for all parties, and specific skills are required to deliver

¹⁴ L Leape, "Preventing Medical Accidents: Is 'systems analysis' the answer?" (2001) 27 *American Journal of Law and Medicine* 145.

¹⁵ See Massachusetts Coalition for the Prevention of Medical Errors, *When things go wrong: responding to adverse events* (2006) 19.

bad news in a sincere, compassionate, and thoughtful way.¹⁶ Effective communication and empathy is pivotal to the open disclosure process.¹⁷

RELEVANT RIGHTS UNDER THE CODE

- Right 1 provides that consumers have the right to be treated with respect. Respect requires a truthful and sensitive discussion about any harm or incident affecting the consumer.
- Under Right 4(1), providers have an obligation to provide services with reasonable care and skill. Provider organisations have an organisational duty of care, which includes the need to have a policy on open disclosure that is well understood and implemented by all personnel.
- The provision of information in a form, language, and manner that enables the consumer to understand the information provided is required by Right 5(1). Right 5(2) also applies, as it requires an environment that supports open, honest, and effective communication.
- Right 6(1) affirms the right to the information that a reasonable consumer, in that consumer's circumstances, would expect to receive. It is seldom reasonable to withhold information about a consumer from that consumer.
- Health and disability services providers have a duty of open disclosure under Right 6(1)(e) according to legal, professional, ethical, and other relevant standards.
- Right 6(3) gives consumers the right to honest and accurate answers to questions relating to services, including information about the identity and qualifications of providers and how to obtain an opinion from another provider.
- Right 6(4) gives consumers the right to receive, on request, a written summary of information provided.
- Right 8 — the right to have a support person(s) present — is particularly relevant in distressing situations and when people receive bad news or a shock.
- Right 10 also requires providers to ensure that consumers are made aware of their right to complain and provided with information about the complaint process and their options.

¹⁶ Senior Medical Officer Dr C and Lakes District Health Board — A Report by the Health and Disability Commissioner, Case 17HDC00191. Available online at www.hdc.org.nz.

¹⁷ See Australian Council for Safety and Quality in Healthcare, *Better communication, a better way to care*, February 2014.