

Disabled People and the Right to Health Care

Background: There has been much attention recently in the media about disabled people's right to terminate medical treatment and/or end their lives. However information about how disabled people can challenge refusals by health professionals to provide treatment has been missing from these debates.

This factsheet tries to redress this balance by informing people about their right to treatment and explaining some of the more technical terms used by health staff, which can often be confusing.

What is a DNR/DNI? A Do Not Resuscitate (DNR) order is a type of advance statement, which informs a doctor not to resuscitate an individual should his or her heart stop. A Do Not Intubate (DNI) order does the same in relation to the insertion of a breathing tube, should a patient start having difficulty breathing. If you are concerned about DNR/DNI's, it may be worth asking the hospital if they have any policies relating to either intubation or resuscitation.

Can a DNR/I notice be added to my medical notes without my knowledge?

No, guidance for all health professionals makes it clear that DNR/Is should only be issued once they have been discussed with the individual and his or her family. If a DNR/I order is placed on your file without your knowledge this is likely to be unlawful and you should complain/seek the advice of a solicitor without delay. It is obviously crucial that this document is removed from your file without delay.

What is an Advance Decision/Statement? These documents set out the medical treatment you would like to receive, or not to receive, if you lose the capacity to communicate such wishes. Such statements usually include information about the circumstances in which you would like to receive treatment, the circumstances in which you would prefer not to and if, for example, there is someone with whom you would like doctors to discuss your treatment when decisions need to be made. Copies of these statements should be given to all those involved in your care and must be taken into account by health professionals in determining your treatment.

Can treatment be withheld or withdrawn without my consent? Doctors are not required to provide treatment that they believe is futile, clinically inappropriate, burdensome, or which cannot be offered for other reasons, such as cost. However, before any treatment is withdrawn, this must first be discussed with the

patient (or their family if the patient is unable to communicate their wishes). Also, if you are not happy with the proposed withdrawal of treatment, you are entitled to request a second opinion.

What can I do if I am not happy with my treatment? You can complain verbally or in writing. Most hospitals will have a complaints manager who should make a written record of your complaint. If your complaint is not resolved successfully after local resolution, you can complain to the Parliamentary and Health Service Ombudsman, who are independent of the NHS and government.

What is the ‘Best Interest’ checklist? This is a requirement under the Mental Capacity Act to protect the rights of people who are unable to make decisions for themselves. The checklist includes a requirement that health professionals should not make a decision about life-sustaining treatment for a person “motivated by a desire to bring about his (or her) death”.

What is PALS? The Patient Advice and Liaison Service (PALS) provide a confidential service that is designed to help patients get the most from the NHS. They can tell you more about the NHS complaints procedure and they may be able to help you to resolve your complaint informally.

What is ICAS? The Independent Complaints Advocacy Service (ICAS) is a national service which supports people who wish to make a complaint about their NHS care or treatment. Although a national service, ICAS is delivered by 3 voluntary sector organizations: The Carers Federation, POhWER and South of England Advocacy Project.

What if my local NHS Trust refuses to follow the terms of my Advance Statement/Decision? An advocate or someone close to you could challenge this by arguing that doctors were not acting in line with your wishes and/or your best interests. If the matter went to court, they would listen and take account of your views and those of the NHS Trust in order to decide whether the Trust is acting in your best interests or not.

What legal action can I take? There are a number of legal options open to patients in dispute with their doctor(s) and/or hospital. For example, a ‘pre action protocol’ provides a legal framework for resolving disputes between patients and their healthcare provider. Also, a ‘judicial review’ can be pursued when someone wishes to challenge a decision or action by a public body, and all other forms of appeal have been exhausted. However, it is strongly advised that legal advice is sought from a solicitor specialising in public health law before any legal action is taken.

Where can I get more information and support? We have listed contact details for all the organisations mentioned in this resource. In addition, The Disability Law Service runs a national telephone helpline and campaign groups such as 'Not Dead Yet' and 'Care Not Killing' are valuable sources of information. Also, the Law Society can provide you with details of solicitors specialising in public health law.

Contacts

British Medical Association:

Tavistock Square, London WC1H 9JP
Tel: 0207 387 4499 Web: www.bma.org.uk

The Royal College of Nursing:

20 Cavendish Square, London, W1G 0RN
Tel: 020 7409 3333 Web: www.rcn.org.uk

Parliamentary & Health Service Ombudsman:

Millbank Tower, London SW1P 4QP
Tel: Helpline: 0345 015 4033 Textphone/Minicom: 0300 0614298
Email: phso.enquiries@ombudsman.org.uk Web: www.ombudsman.org.uk

The Mental Capacity Act 2005:

More information and copies of the Act and the code of practice can be obtained from: The Office of the Public Guardian, PO Box 16185 Birmingham B2 2WH
Tel: 0300 456 0300 Textphone: 0115 934 2778
Email: customerservices@publicguardian.gsi.gov.uk
Web: http://www.direct.gov.uk/en/Governmentcitizensandrights/Mentalcapacityandthelaw/Makingdecisionsforsomeoneelse/DG_186479

The Patient Advice and Liaison Service:

c/o Staffordshire Moorlands Community & Voluntary Services, Bank House,
20 St Edward Street, Leek, Staffordshire ST13 5DS
Web: www.pals.nhs.uk

Independent Complaints Advocacy Service (ICAS) The Carers Federation:

(provides ICAS in the North West, North East, East Midlands, Yorkshire and Humberside), 1 Beech Avenue, Sherwood Rise, Nottingham NG7 7LJ.
Tel: 0115 985 8485 Email: info@carersfederation.co.uk
Web: www.carersfederation.co.uk/what-we-do/icas/

POhWER:

(provides ICAS in the West Midlands, London and the East of England), Carol Warren House, Lonsdale Road, Stevenage, Hertfordshire SG1 5DZ
Tel: 01438 727192 Web: www.pohwer.net

South of England Advocacy Projects:

(SEAP provides ICAS in the South East and South West of England),
7th Floor Cavendish House Breeds Place, Hastings East Sussex TN34 3AA
Tel: 0330 440 9000 Email: info@seap.org.uk Web: www.seap.org.uk/icas/

The Resistance Campaign: Web: www.theresistancecampaign.org.uk

Not Dead Yet: Web: www.notdeadyetuk.org

Care Not Killing: Web: www.carenotkilling.org.uk

Disability Law Service:

39-45CavilStreet, London, E1 2BP
Tel: 020 7791 9800 Minicom: 020 7791 9801
Email: advice@dls.org.uk Web: www.dls.org.uk

The Law Society:

113 Chancery Lane London WC2A 1PL
Tel: 020 7242 1222 Web: www.lawsociety.org.uk

This information sheet is also available in other formats, including: large prints, Braille, audio and electronically

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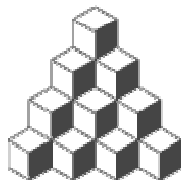
GMCDP, BEVC, Aked Close, Ardwick, Manchester. M12 4AN

Phone: 0161 273 5154 Text Relay: 08001 0161 273 5154 Fax: 0161 273 6141

Email: info@gmcdp.com

Web: www.gmcdp.com

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