



For better  
mental health

# The Mind guide to advocacy

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*'I have an assessment coming up for my incapacity benefit, which is worrying me. I could do with some support!'*

*'Very often it feels like it's you against the hospital. Somebody to help you would make you feel stronger and more secure. An advocate could help you to express your views in a constructive way.'*

*'People don't need an advocate all the time. But they need to know that advocacy is available and how to make contact, if the need arises.'*

**An advocate is someone who can both listen to you and speak for you in times of need.**

## **What is advocacy?**

Mental health advocacy has developed in the United Kingdom, over the last twenty years, as one way of challenging the discrimination faced by users and survivors of the mental health system. Advocacy in all its forms seeks to ensure that people are able to speak out, to express their views and defend their rights.

Having a mental health problem, or experiencing mental distress, often means that your opinions and ideas are not taken seriously, or that you are not offered the opportunities and choices you would like. Being labelled with a diagnosis of mental illness is often linked to poverty, unemployment and exclusion from everyday life. In its simplest form, advocacy can mean just listening respectfully to someone.

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For people who already experience discrimination and exclusion on the basis of their ethnic or cultural background, physical disability, gender, sexuality or age, having a mental health problem creates another barrier to social inclusion. It can make voicing opinions, wants and needs almost impossible.

Advocacy is a process of supporting and enabling people to:

- express their views and concerns
- access information and services
- defend and promote their rights and responsibilities
- explore choices and options.

An advocate might help you access information you need, or go with you to meetings or interviews, in a supportive role. In some cases, you might want your advocate to be more active. An advocate might write letters on your behalf, or speak for you in situations where you don't feel able to speak for yourself.

Friends, family and mental health professionals can all be supportive and helpful, but this may be difficult for them if you are doing things they disagree with, even though it's what you want. Health and social services staff have a 'duty of care' to the people they work with, which means that they can't support you in doing things that they think will be bad for you. But an advocate is independent, and will represent your wishes without judging them or putting forward their own personal opinion.

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## What kind of advocacy do I need?

There are different kinds of advocacy, and diverse communities and groups understand advocacy in different ways, but advocacy in all forms shares some core beliefs. An advocate respects the views and wishes of the person they advocate for, without judgement, and believes in their right to access information, representation, services and opportunities.

Although some advocates may be legally or medically qualified, in general, advocates are volunteers or paid workers who have been trained by the project or group they are part of. You can expect an advocate to have been given training in listening and negotiating skills. They should also have a knowledge of the basic legal framework and provision of mental health and community care services.

### Self-advocacy

Self-advocacy is about speaking up for yourself and making your views and wishes clear. This can be very difficult to do at times, and there are skills and tools that can support self-advocacy, such as assertiveness training, crisis cards or advance decisions (formally known as 'advance directives'), which set out your wishes in case of any crisis. (Also see Mind's booklet *How to assert yourself*.)

Self-advocacy groups are groups of people who support each other in developing and using self-advocacy skills. Many people see self-advocacy as the ultimate aim of other forms of advocacy work. Most local user and survivor groups promote and include self-advocacy.

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## Group advocacy

Group advocacy (also known as collective advocacy) is where a group of people with similar experiences meet together to put forward shared views. Local mental health service-user groups, support groups and patient councils are all examples of group advocacy. There are also larger national groups, such as those that appear under 'Useful organisations', which campaign and advocate about issues raised by their membership. (See p. 13 for details.)

## Peer advocacy

Peer advocacy is support from someone with experience of using mental health services. Peer advocates can draw on their own experiences to understand and empathise with the person they are working with. Working with a peer advocate makes it easier for advocate and user to have an equal relationship. Some peer advocates and advocacy schemes work on an entirely voluntary basis, but the majority are now funded user- and survivor-run schemes with paid workers.

## Formal, professional, or paid advocacy

Many voluntary organisations have developed advocacy services, which train and pay some or all of the advocates to work with anyone who wants to use their service. Although not always the case, this kind of advocacy is usually focused on short-term or 'crisis' work, rather than providing long-term support. Many of the advocates working for formal advocacy services are also users and survivors.

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### Citizen advocacy

Citizen advocacy matches people with partners who are members of their local community. Citizen advocacy partnerships tend to be long-term, supportive relationships. Most citizen advocacy schemes have paid coordinators, who train and support unpaid volunteer partners. As well as helping with specific situations, citizen advocacy partnerships are intended to support vulnerable people so that they can take a greater part in the life of their community.

### Legal advocacy

People with specialist knowledge and training, such as lawyers and advice workers, are sometimes called 'legal advocates'. Legal advocates differ from other mental health advocates in that they represent people in formal settings, such as courts, tribunals or complaints processes. A legal advocate will often give advice and express their opinion about the best course of action.

### 'Best interests' (non-instructed) advocacy

'Best interests' advocacy is where an advocate represents what he or she feels a person's wishes would be, if they were able to express them. 'Best interests' work is not generally appropriate in mental health advocacy where people are well able to express their needs and opinions directly. Some mental health advocates working with older adults are trained to do 'best interests' work with those clients with dementia who are no longer able to communicate clearly. A specific example of 'best interests' advocacy is provided by Independent Mental Capacity Advocates (IMCAs) under the Mental Capacity Act 2005 (see p. 8).

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## **When might I need an advocate?**

Advocacy can be helpful in all kinds of situations where you are finding it difficult to make your views known, or to make people listen to them and take them into account. Mental health advocacy often focuses on accessing, using or complaining about mental health and community care services. Other common areas of work are connected with benefits, employment and education opportunities.

### **Advocacy in hospitals**

The experience of an inpatient admission, whether voluntary or under a section of the Mental Health Act (MHA), can be confusing and disempowering. Exercising your right to be informed and involved in your own care and treatment is difficult when you are distressed or when your views may be discounted as part of your 'illness'.

In hospital, an advocate will help you get information about your legal rights, your medication or discharge plans. Advocates can be helpful in preparing for Mental Health Review Tribunals and other meetings, and can often attend meetings with you. If you want support on day-to-day issues in hospital, such as getting food that is appropriate to your religious or cultural background, or making sure your belongings are safe, an advocate will support you in making your concerns known to the staff. An advocate can assist you in finding out about the services that might be available when you leave hospital. Where you are unhappy with the service you are receiving, an advocate can support you through the complaints process.

If you are in hospital under a section of the MHA, you may be entitled to help from an Independent Mental Health Advocate (see p. 8).

### Advocacy in the community

In the community, an advocate might assist you with a benefit claim, finding the right housing, or getting the community care services you want. An advocate can provide support if you want to complain about services you are not happy with. They might also help you find out about work, education or leisure opportunities in your area.

### Advocacy under the Mental Capacity Act 2005

The Mental Capacity Act 2005 applies to people who lack the mental capacity to make a particular decision. The Act states that in certain situations, an **Independent Mental Capacity Advocate (IMCA)** must be appointed to help people who lack capacity to make a decision and have no one else to speak on their behalf. This could happen when an NHS body wants to provide 'serious medical treatment' or there are plans to provide the person with long-term accommodation in hospital or a care home. Note, if the person is detained under the Mental Health Act 1983 then the Mental Capacity Act does not apply and there is no duty to provide an IMCA.

### Advocacy under the Mental Health Act 1983 (MHA)

Certain people – called 'qualifying patients' – are entitled to help and support from **Independent Mental Health Advocates (IMHAs)**. This includes people who have been detained under the MHA for longer than 72 hours, such as those under sections 2 and 3, and people living in the community under Mental Health Act guardianship, conditional discharge and supervised community treatment. Others who are not 'qualifying patients' but who are receiving treatment in hospital for mental health problems may also be entitled to IMHA support if they are considering certain treatments under the MHA, such as neurosurgery and electro convulsive therapy.

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Information on IMHAs and how to contact them should be given to a person if they are admitted to hospital or accepted into guardianship. IMHAs can also be contacted by family members, nearest relatives, and certain mental health professionals involved in the person's treatment. Note: a person is not obliged to accept help from IMHAs if they don't want to.

The role of an IMHA is to provide information or help obtain advice on any rights that a person or others, such as their nearest relative, may have under the MHA, on any MHA powers being used by professionals which affect them, and any medical treatment offered to them, or being considered, in connection with their care under the MHA. It may be possible for IMHAs to assist with complaints about a person's care and treatment under the MHA or to resolve problems with the services received under the MHA while in hospital or in the community. An IMHA cannot apply to a mental health tribunal on a person's behalf, but can obtain information needed for a tribunal or assist in other ways. IMHAs are entitled to interview professionals and inspect medical records in connection with their role in assisting a person, as long as that person agrees.

When a person is discharged from a section or supervised community treatment and they are no longer receiving care and services under the MHA, their entitlement to IMHA assistance will end, but advocacy support may be available from other services, such as local mental health advocacy groups.

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## **Who are the services for?**

Most mental health advocacy services work with anyone in their area who wants to use the service. If you are having difficulty making your voice heard, or would like support or information about a situation you find yourself in, then you might like to talk to your local service.

Although some advocacy services have been set up to meet the needs of specific groups (such as minority ethnic communities, older adults, children, or gay, lesbian and bisexual people), most advocacy services are 'generalist'. This can make it harder to work with the advocates, as they may not understand your experience or the issues you face. If English is your second language, it may be difficult to find an advocate who can speak your community language.

If you would like an advocate from a specific group or community, and do not have a service in your area, try asking the generalist service. They may have an advocate with a similar background, or be able to accommodate you by making an arrangement with another service.

## **How do I find a suitable advocate?**

If you would like to find out about advocacy services and groups in your area, you could start by contacting national organisations such as Mind (see 'Useful organisations', on p. 13). You could also contact your local Mind association, Patient Advice Liaison Service (PALS) in England, or Community Health Council in Wales.

Community Health Councils provide assistance and support with complaints about NHS services in Wales. Check your phone directory or call the Wales Board on 0845 644 7814 for local offices. PALS (Patient Advice Liaison Services) are provided by local NHS Trusts to resolve immediate problems and give information about pursuing NHS complaints in England. They are not independent of the hospital, but can refer people to an Independent Complaints Advocacy Service (ICAS). For your local PALS service, ask at your local hospital or GP surgery, or phone NHS Direct on 0845 46 47.

Unfortunately, not all areas have established mental health advocacy groups. If you don't have an advocacy service or group in your area, there are other organisations as well as PALS or Community Health Councils that might be able to provide support and advice, including local voluntary services and Citizens Advice Bureaux (see 'Useful organisations', on p. 13).

### **How do I work with an advocate?**

It is important that you find an advocate you are comfortable working with. Make sure you discuss with your advocate how they operate, and what you do and don't want them to do. These are some practical questions you might want to ask:

- How will I contact you, and when are you available?
- Can you come to meetings and appointments with me?
- What issues can you help me with?
- What can't you help me with?
- What records do you keep and who sees them?
- What is your confidentiality policy? What things won't you keep confidential?
- If you do something I am not happy with, how can I complain?
- Can you work with me if I am in hospital or if I am in the community?

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You can usually take an advocate into health and social care meetings. The exception is where your psychiatrist believes that having an advocate present will have a significantly adverse affect on your mental health or might disrupt the meeting.

### **What if no formal advocacy is available in my area?**

#### **Self-advocacy or group advocacy**

In most areas there is a local user and survivor group that will already do self- and group advocacy work, on an informal basis. You can develop your own and others' advocacy skills by using some of the resources listed at the end of this booklet, or by taking part in local training programmes. If you are interested in working towards more formal self- or group advocacy, you should contact one of the organisations listed on p. 13.

#### **Citizen advocacy or formal advocacy**

If there is no advocacy scheme in your area and you are interested in supporting advocacy development, you might think about doing some of the following things:

- Contact your local Community Mental Health Team (CMHT) in England, or Health Authority in Wales. These bodies often commission advocacy services. You could ask what the plans are for developing advocacy in your area.
- Contact organisations that can help with advocacy development (see 'Useful organisations').
- Contact nearby user and survivor groups and voluntary organisations to talk about local services and local need.

## Useful organisations

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### **Mind**

Mind is the leading mental health organisation in England and Wales, providing a unique range of services through its local associations, to enable people with experience of mental distress to have a better quality of life. For more information about any mental health issues, including details of your nearest local Mind association, contact the Mind website: [www.mind.org.uk](http://www.mind.org.uk) or MindinfoLine on 0845 766 0163

### **Action For Advocacy (A4A)**

tel. 020 7820 7868 web: [www.actionforadvocacy.org.uk](http://www.actionforadvocacy.org.uk)  
Information and training on all forms of advocacy

### **Citizens Advice**

admin tel. 020 7833 2181 web: [www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)  
information online: [www.adviceguide.org.uk](http://www.adviceguide.org.uk)  
Confidential advice on a range of issues. Locations include within hospitals. See their website or your local phone directory for their nearest office

### **Equality and Human Rights Commission**

helplines: England: 0845 604 6610, Wales: 0845 604 8810  
web: [www.equalityhumanrights.com](http://www.equalityhumanrights.com)  
Advice and information on discrimination and human rights issues

### **Together (formerly MACA)**

tel. 020 7780 7300 web: [www.together-uk.org](http://www.together-uk.org)  
Supports people with mental health problems

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**Older Persons Advocacy Alliance (OPAAL)**

The Beth Johnson Foundation, Parkfield House, 64 Princes Road, Hartshill, Stoke-on-Trent ST4 7JL

tel. 01782 844 036 web: [www.opaal.org.uk](http://www.opaal.org.uk)

Promoting independent advocacy services for elderly people

**PACE**

tel. 020 7700 1323 web: [www.pacehealth.org.uk](http://www.pacehealth.org.uk)

Promotes lesbian and gay wellbeing – has mental health advocacy service

**WITNESS (formerly POPAN)**

tel: 020 7922 7800 web: [www.popan.org.uk](http://www.popan.org.uk)

Support for people abused by health or social care workers

## Further reading

- How to assert yourself* (Mind 2010) £1
- How to cope with hospital admission* (Mind 2004) £1
- How to parent in a crisis* (Mind 2009) £1
- Legal rights and mental health: the Mind manual* (Mind 2009) £55
- Making sense of antidepressants* (Mind 2008) £2.50
- Making sense of antipsychotics (major tranquillisers)* (Mind 2007) £2.50
- Making sense of electroconvulsive therapy (ECT)* (Mind 2008) £2.50
- Making sense of lithium and other mood stabilisers* (Mind 2009) £2.50
- Making sense of sleeping pills and minor tranquillisers* (Mind 2008) £2.50
- The Mental Health Act 1983: an outline guide* (Mind 2010) £1
- Mind rights guide 1: civil admission to hospital* (Mind 2009) £1
- Mind rights guide 2: mental health and the police* (Mind 2009) £1
- Mind rights guide 3: consent to medical treatment* (Mind 2009) £1
- Mind rights guide 4: discharge from hospital* (Mind 2010) £1
- Mind rights guide 5: mental health and the courts* (Mind 2008) £1
- Mind rights guide 6: community care and aftercare* (Mind 2009) £1
- With us in Mind: service user recommendations for advocacy standards in England* (Mind 2006) £5
- Understanding anxiety* (Mind 2008) £1
- Understanding depression* (Mind 2010) £1
- Understanding mental illness* (Mind 2007) £1
- Ward watch: Mind's report on hospital conditions for mental health patients* (Mind 2004) £5

## Order form

If you would like to order any of the titles listed here, please contact

Mind Publications, 15–19 Broadway, London E15 4BQ  
tel. 0844 448 4448, fax: 020 8534 6399  
email: [publications@mind.org.uk](mailto:publications@mind.org.uk)  
web: [www.mind.org.uk](http://www.mind.org.uk)

(Allow 28 days for delivery.)

## Mind's mission

- Our vision is of a society that promotes and protects good mental health for all, and that treats people with experience of mental distress fairly, positively, and with respect.
- The needs and experiences of people with mental distress drive our work and we make sure their voice is heard by those who influence change.
- Our independence gives us the freedom to stand up and speak out on the real issues that affect daily lives.
- We provide information and support, campaign to improve policy and attitudes and, in partnership with independent local Mind associations, develop local services.
- We do all this to make it possible for people who experience mental distress to live full lives, and play their full part in society.

For details of your nearest Mind association and of local services contact Mind's helpline, MindinfoLine: **0845 766 0163** Monday to Friday 9.00am to 5.00pm. Speech-impaired or Deaf enquirers can contact us on the same number (if you are using BT Textdirect, add the prefix 18001). For interpretation, MindinfoLine has access to 100 languages via Language Line.

Scottish Association for Mental Health tel. 0141 568 7000

Northern Ireland Association for Mental Health tel. 028 9032 8474

**This booklet was written by Nancy Kelley**

First published by Mind 2000.

Revised edition © Mind 2010

ISBN 978-1-874690-08-5

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