

Restraint in mental health services

Influencing change
in your area



Acknowledgements

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This guide sets out how you can get involved in influencing the use of restraint and other restrictive interventions in mental health services. It goes with a companion report, *Restraint in mental health services: What the guidance says*, which gives you the background information you will need.



This information was written and produced by Mind's Policy & Campaigns team in partnership with the National Survivor User Network.

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Working as a campaigner... has given me an overriding passion. My confidence has grown and I've acquired a host of new skills.

Introduction

What this guide is for

Together with our report *Restraint in mental health services: What the guidance says*, this practical 'how to' is a resource for people who want to change the practice of restraint in mental health services and end the use of force, particularly on adult mental health wards. It is mainly aimed at people who use mental health services, carers, advocates and campaigners.

This guide for campaigners provides practical information about how you can influence practice. Its companion report, *Restraint in mental health services: What the guidance says*, provides information about restraint, people's experiences, official guidance, good practice and campaigners' stories. You could give a copy to people you are trying to influence.

What we aim to achieve

We want to spread good practice and end the use of force. Both Mind and NSUN have campaigned for people using mental health services to be treated fairly, positively and with respect. Mind's 2013 campaign about the use of physical restraint helped lead to new national guidance in England, *Positive and proactive care*. Now we hope that more people will get involved in shaping policies and improving practice.

Across the country, our members continue to report experiences of a mental health system where people face an ongoing battle to exert control and to establish and exercise basic rights.

NSUN Manifesto (2015)

How you can use it

You can use this guide to campaign as an individual, or with a group, although campaigning as a group can be more effective and more supportive for you. We know that it can be very difficult to challenge practice, make complaints and have a voice. The contact numbers and resources in this guide are there to support you on the journey.

How can I get involved in changing the use of restraint?

Find out what your local involvement options are

Contact the organisation that runs your mental health services

This will be an NHS Trust in England or Health Board in Wales. You'll find details in the phone book, on the web and from NHS Choices or Health in Wales. You could look out for:

- Job titles like:
 - Patient and public involvement manager
 - Patient liaison officer
 - Engagement team lead
 - Recovery lead
 - Patient experience manager
- Pages on the website called 'service user and carer experience', 'patient experience', 'get involved' or 'customer relations'.

Contact your local Patient Advice and Liaison Service

Your local PALS can help to find the right information. Their contact details will be on the web and in the phone book.

Contact a local mental health group or other community group

Your local Council for Voluntary Service will know what is in your area and your local Healthwatch (in England) or Community Health Council (in Wales) will know about any health-related groups and forums. Mind and NSUN have local contacts on their respective websites mind.org.uk / nsun.org.uk

4Pi Standard for Involvement

Meaningful involvement of service users and carers is important because it can transform individual lives, improve services and build resilience within communities. The National Involvement Partnership project, led by NSUN and made up of mental health service users and carers, has developed national standards for involvement.

Motivated by the motto 'Nothing about us without us', their aim was to 'hard wire' the service user and carer voice and experience into the planning, delivery and evaluation of health and social care services. The framework is based on **principles, purpose, presence, process** and **impact** (4Pi) and is simply a means to enable services, organisations and individuals to think about how to make involvement work well.

Involvement for Influence: The 4Pi Standard for Involvement (NSUN, 2014) is available from nsun.org.uk or 020 7820 8982

Link up to an existing service user involvement initiative

Some of these suggestions are suitable for individual action but we recommend joining up with a group where you can.

Restraint reduction initiatives

Your mental health service provider may already be working with service users to improve practice and reduce the use of restraint. This might include a programme such as those on page 17. In fact, if organisations in England are following their guidance, they should have a programme to reduce the use of restraint in place. This is likely to be the best and most straightforward way to get involved.

Service user involvement initiatives

If your mental health service provider doesn't have a project about restraint, they should have other ways for you to feed back your experiences and to help shape the service. For example:

- Advisory groups (eg. on new policies or training programmes)
- Working directly with staff to design services, policies or training ('co-production')
- Mystery shoppers – a structured way for service users and carers to give real time feedback of what services are like

- Inspections, service review and redesign, assessing the environment (eg. in England, patient-led assessments of the care environment (PLACE), or the 15 Steps Challenge – a toolkit for looking at the quality of care based on service users' first impressions of a ward)
- Involvement in staff recruitment – particularly good for assessing candidates' values
- Mentoring student nurses or other involvement in staff training – one-to-one mentoring of a mental health professional, or sharing stories in a training session, can powerfully influence staff development and understanding
- Involvement in research, for example designing and carrying out interviews with other service users.

If places on a project are limited or you don't want to be so involved, you can find out how to share your views and experiences with service user representatives and support their involvement/work.

Meet with your mental health service provider

You could ask for a meeting as an individual, or act as a representative for your group. You could also invite someone from the organisation to come and meet with your group.

Purpose of the meeting

There are different things you might want to get out of a meeting with your trust or board, for example:

- Fact-finding
- Raising concerns and saying what you would like to happen
- Proposing ways to be involved or specific initiatives
- Trying to build a positive relationship.

When I have been involved in influencing local practice I have always felt included and felt that my opinion mattered.

Who to meet with

Who can make the change you want to see?
Different options are:

- Senior management – the Chief Executive or Chair of the organisation
- Senior staff with responsibility for restraint, patient safety or service quality, for example:
 - Director of Nursing, Quality and Patient Experience (or similar job title)
 - Clinical Director for adult or acute mental health (or similar job title)
- Someone you know already who has influence and will be a good ally, or ask for advice from one of the people listed on page 6.

If it is an independent (private) hospital you can contact the company headquarters or the Director or Manager of the particular hospital.

Preparing for the meeting

Decide what you want from the meeting and tell the person in advance what you want to cover. Always have something to ask that will lead to an action! One of the strengths you will bring is your lived experience; think about how you will draw on this, how it will serve the purpose of your meeting and how a breadth of experience, not just of one individual, will bring greater value.

Things you could research beforehand:

- What people's experiences are locally and/or what good practices you want the service provider to adopt
- Statistics – It is hard to interpret an individual organisation's statistics if you don't know what the national picture is. See page 11 in our report *Restraint in mental health services: What the guidance says* for more information about available statistics.
- What the organisation has said about its policies and practice
 - Quality account (in England) or Quality statement (in Wales) – this is your trust's or board's annual progress report on how it is improving the quality of its services. All services in England must publish an annual report about their use of restrictive interventions. Check the organisation's website (eg the 'About us' pages) or call them to request it.
- Policy – the organisation's policy on the use of restraint (eg 'Prevention and management of violence and aggression') should be on their website as well, or available on request. What do you think of it, and how does practice match up?
- How others have rated the service – in England there are ratings of services by people who have used them, the CQC, and against various performance measures on (see page 18 for other contact details):
 - Patient Opinion – an independent UK site for people to share their experiences of health care, good or bad – patientopinion.org.uk
 - NHS Choices (England) – nhs.uk
 - My NHS (England) – another section of nhs.uk that is in development and has different sets of ratings for different types of services.
 - Care Quality Commission (England) – cqc.org.uk or follow the link from the trust's own website or the NHS Choices' page on the hospital concerned to see the latest report
 - Health Inspectorate Wales – publishes its inspection reports on mental health units – hiw.org.uk.

Questions you could ask in the meeting

- What strategies to reduce restraint do you use? How are service users and carers being involved?
- Are you reviewing your policies in the light of the guidance (England), and how are service users and carers being involved – do they have an equal influence?
- Have you published a report on your organisation's use of restraint and seclusion?
- How will you monitor outcomes of the guidance and how will service users and carers be involved in that?
- Is every service user who is subjected to restraint offered the opportunity to share their perspective on it, and how is this recorded?
- NICE (England) says there should be a service user experience monitoring unit led by service users – do you have one, and if not how will you go about setting one up?
- What training do you provide for staff, and are service users involved in design and delivery?
- What data do you collect and what does it show? How does it compare with similar organisations and the national picture, does it relate to service users from marginalised communities, and does it differentiate:
 - The number of incidents and number of people restrained
 - Use of face down / prone restraint – how often it is used and how much as a proportion of all physical interventions
 - Use of restraint to administer medication
 - Police involvement
 - Physical injury – what is counted as physical harm
 - Psychological harm
 - Use of seclusion – incidents, people, duration
 - Number of complaints.
- Do you collect data from service users and carers as well, and what does that show? How do you learn from this?
- Who is the board level lead for reducing restraint, and how do they ensure service users and carers are supported to be involved?
- Are any of your staff in the Positive and Safe Champions' Network (England)?

Making the most of the meeting

- Think about what follow-up you want – for instance to be invited to be involved in a particular initiative, to be given particular information, to get representatives of the organisation to come and speak to your group or listen to more people directly. What will they do as a result of your meeting?
- Get information in writing so you can refer back to it and take it back to your group
- Leave information you want the organisation to have, for example a copy of our report *Restraint in mental health services: What the guidance says*
- Agree a follow-up that gives you time to agree priorities with your group and the service provider time to respond. During this time you could review whether you were talking to the right people.

Campaigning to change your local services

This section gives advice on how you can get involved in campaigning if nothing changes at first. For information about how to complain or report bad practice to responsible bodies please see page 15. Challenging bad practice through complaints and other channels will reinforce campaigning.

Everything in the previous section still applies to campaigning. It is important to keep communicating with the service provider. If you did not get anywhere with meeting less senior staff consider asking to meet with the top management.

Planning a campaign

- Decide what you are trying to achieve
- Gather your evidence – for example, service users' experiences (you could use or adapt the questions in the box on the next page for a survey or group discussion), statistics, and good practices. You might need to look again at what you are trying to achieve once you have more evidence.
- Decide who to approach – think about who can make the change you want, eg the trust or board management or key staff. Think about who influences them, who else they will listen to, eg staff; in England the Clinical Commissioning Group, Care Quality Commission, local Healthwatch, or your MP; in Wales the Health Inspectorate Wales, Community Health Council or your AM; the general public.
- Activities to get your message across
 - Present your evidence – depending on your audience, what your evidence is and the resources you have, this could be a written report, speaker meeting, powerpoint presentation, podcast, video clips
 - Meet your MP or AM – they might champion your cause and help arrange meetings or visits
 - Use local media to get public support – write a letter, or provide a story (eg around an MP or AM visit or evidence you have collected) – you could contrast your area with a neighbouring or similar area if they are doing better
 - Use social media to raise awareness of your campaign and win support
 - Aim to keep communicating and collaborating with the service provider/staff, make allies, stay positive and persist.
- You can also create change directly through peer support, for example sharing experience of calming or grounding techniques.

Linking to a national campaign

Linking into a Mind, NSUN or other national campaign means you can make the most of the profile and awareness they raise. You will be contributing to a wider movement and can draw on their support so you are not on your own.

You could:

- Use national activity to push your local campaign, for example
 - following up national news stories with social media comment or letters or offers of interviews to local media
 - using a national report to start or renew conversations with your service provider, MP or AM
- Take campaign actions organised by the national campaign
- Share your knowledge with the national campaign and help by offering your local experiences as an example to include in campaign reports, media work or web pages
- Make contact with other groups and exchange your campaigning experience.

Recognising your achievements and taking stock

Change can happen quickly but often it comes gradually and in small steps. It is important to take time to recognise and celebrate what you have done, and to acknowledge any positive changes the service provider has made. Even if your end goal seems a long way off, every difference you make counts. It is also good to take stock of where you are and think about whether you are going to keep going, do something differently or take a break.

Questions you could use to gather people's experiences and views of restraint

- What is your definition/meaning of coercion, control and restraint?
- Have you experienced or witnessed coercion, control and restraint?
- What are your thoughts or views about your experiences of control and restraint in mental health services?
- On the basis of this experience, what has been helpful and what needs to change?
- If you were subject to coercion control and restraint, were you ever given the chance to debrief / to record what might be improved by all?
- What are your recommendations for aftercare and grounding techniques?
- What impact, if any, do you think that factors such as your ethnicity, gender, sexual orientation or age had on the amount of restraint which mental health professionals used with you?
- What challenges might staff face?
- How do you feel about making a complaint and the complaint making process?
- Is there anything else you want to add that hasn't been covered?

What difficulties might I face as a campaigner and how can I tackle them?

Issues that could arise with your service provider

Lack of openness to service user expertise

Not everyone understands the value of expertise that comes through experience. Sometimes involvement is done as a 'tick box' exercise and people's views aren't really heard.

Try and find allies who should include staff whose job it is to do engagement (see page 6). You could jointly, with other service users, approach senior staff to explain why you are not satisfied. Refer them to resources such as NSUN's 4Pi Involvement standards, and good practice examples such as those in our companion report *Restraint in mental health services: What the guidance says*.

Inadequate recognition of unacceptable uses of restraint

There is the potential for staff to become institutionalised and desensitised. Staff may anticipate they are going to need to restrain someone and have justifications for its use that do not match guidance or your experience.

You could join a good practice network (see page 7) and ask if the service provider, or its staff, could do the same. Sharing stories and being open to staff fears should help understanding all round.

One type of restraint is used less, but others more

The organisation may focus on reducing one type of restraint, for example physical restraint, but use others, such as rapid tranquillisation or seclusion, more.

Keep an eye on the use of all kinds of restraint and restrictive practice, and challenge the organisation on how it is reducing the need to use any restrictive interventions – the aim of *Positive and Proactive Care*.

Getting drawn in to the organisation's culture and viewpoint

If you succeed in getting involved in, for example, an advisory group or improvement programme, it is possible that you might get drawn in so much that you lose touch with other service users and possibly your own vision.

You can guard against this by keeping in touch with a group – for example reporting back and asking them what they want you to say.

Issues to be aware of in relation to your own wellbeing

Taking on too much

Where there is a lot to change it can be easy to get overwhelmed or 'burnt-out'. Such a difficult topic may be distressing with the potential for re-traumatising.

It is important to look after yourself, for example by:

- Pacing yourself and taking breaks when you need them
- Disclosing your own experience only to the extent you want, when you want, and to whom you want
- Recognising your personal support network and having a clear idea of where you can go if you need support for your mental health
- Getting support, especially at key moments, such as after you have given a talk or taken part in a meeting
- Working with other people as a group.

Being seen as a trouble-maker if you raise concerns

You may feel that you are being treated negatively in the mental health service because of your campaigning activity.

Consider getting support from an advocate or talking to an adviser, for example on Mind's legal line. The more you are connected to other service users, for example in a peer support group, the harder it will be for people to individualise the concerns you are raising and the more support you will have.

You may be able to get support from others who have been in the same situation, so contacting a local service user group could be helpful. There is a list of organisations that will be able to help inform you of your rights or provide support on page 18.

Feeling isolated or getting stuck

Working as a group can help prevent you feel personally isolated, but what if the group needs support?

You could:

- Connect with other local groups – remember to link in with groups representing specific communities or people who experience discrimination
- Join a network
- Link in to a national campaign
- Organise a visit to another trust or board area or a peer support group to swap experiences and keep up interest and momentum
- Follow up the projects in our companion report *Restraint in mental health services: What the guidance says*.

How can I complain or report bad practice and abuse?

Make a complaint

If restraint has been used in any of the following ways to you or to someone you know, you may wish to complain about this, or report bad practice or abuse:

- when it shouldn't have been
- disproportionately
- for too long a time
- to cause pain, punishment or humiliation

If any of these are the case, we suggest that you do raise concerns. We suggest raising these informally first, but if you do decide you want to make a more formal complaint, your options include one or more of the following.

- The service provider is obliged to have a clear complaints policy and procedure, as well as a policy on its use of restraint. You might want to request a copy of these so that you can see what is in them.
- If you are directly affected by bad practice or abuse, you or someone on your behalf are entitled to make a complaint using its formal complaints mechanism. This should enable the organisation to open an investigation into the alleged bad practice or abuse.
- You can complain to the service provider, commissioner, local authority, CQC (England), Health Inspectorate Wales, or the police depending upon what the complaint is about.
- It's appropriate to report abuse to the police where you think a crime has been committed.

Raise your concern with the Care Quality Commission (England) or Healthcare Inspectorate Wales (Wales)

- If you are detained under the Mental Health Act you can also make a complaint to the Care Quality Commission (CQC) who have a particular duty to investigate complaints made by detained patients
- The CQC inspect and regulate all health and care providers in England. They expect providers to have a zero tolerance approach to unnecessary or disproportionate restraint.
- The CQC does not otherwise investigate or resolve individual complaints, but you can contact them if you feel that you, or someone you know, have received poor care. You can tell them about your experience, or what you know about, direct or through Mind's Legal Line.
- The Health Inspectorate for Wales inspects and regulates NHS and independent health care in Wales. Their Review Service checks on the use of the Mental Health Act in Wales and reviewers meet with patients to see how they are being cared for. They can raise issues with managers on patients' behalf.

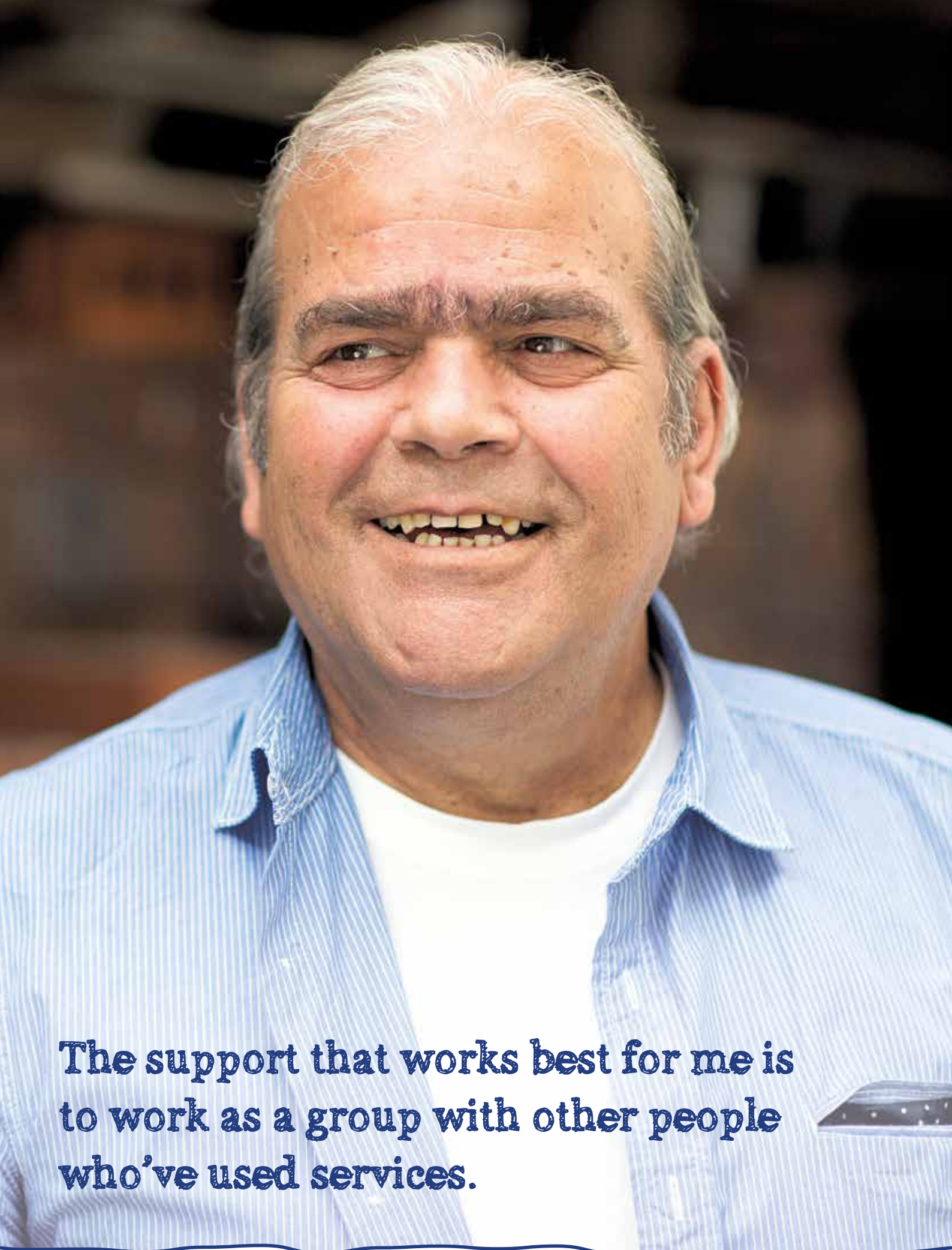
Raise your concern with Healthwatch (England) or Community Health Council (Wales)

- Healthwatch is the health care consumer champion in England. It can raise concerns with the Care Quality Commission. Local Healthwatch is the champion locally and has the power to enter certain health and care premises, including hospitals, and view the care provided.

- Community Health Councils (CHCs) represent the public's views to health bodies in Wales and monitor health care. They can also advise about how to complain. There are eight CHCs, linked to Health Board areas.

Getting support when raising concerns

- It can be very challenging to take action in this way, so it is important to get personal support, for example from a family member, friend or peer support group.
- Mind's Legal Line provides general legal advice. Our advisers can go through some of the options with you, explain your rights and provide further information. There is also information about how to make a complaint on Mind's website.
- NSUN can provide peer support and sign posting, help you navigate through difficult situations and link you with local service user led groups
- PALS (Patient Advice and Liaison Service) are based in the hospital and can help with making complaints
- Healthwatch can help you understand the system and find an advocate. They can also take up your concern themselves.
- An advocate can provide more on the spot support to help you understand and exercise your rights. There is further information about advocacy on mind.org.uk
- Other rights organisations can provide information and advice.
- If you think you might want to challenge the use of restraint because it may have been unlawful, you could seek legal advice on how to do this. There is information on finding a solicitor on the Law Society's website: solicitors.lawsociety.org.uk



The support that works best for me is to work as a group with other people who've used services.

Where can I find out more?

This section contains contact information to support campaigning and making complaints. Our companion report *Restraint in mental health services: What the guidance says* contains further information about guidance on restraint and good practice initiatives.

Involvement and campaigning

Mind

mind.org.uk

020 8519 2122

action@mind.org.uk

Campaigner toolkit due out 2016

NSUN (National Survivor User Network)

Including 4Pi National Involvement Standards

nsun.org.uk

020 7820 8982

Time to Change

time-to-change.org.uk

Time to Change, run by the charities Mind and Rethink Mental Illness, is England's biggest mental health anti-stigma campaign. For campaigning ideas and inspiration.

NCVO's Know How Non Profit

Practical support for community groups

knowhownonprofit.org/

Getting advice and making complaints

Mind

mind.org.uk

Mind Legal Line – 0300 466 6463

9am to 6pm, Monday to Friday except bank holidays

legal@mind.org.uk

Mind LAS, PO Box 277, Manchester M60 3XN

Voiceability

voiceability.org/

01223 555800

NHS Complaints Service

nhscomplaints@voiceability.org

Helpline: 0300 330 545

Textphone: 0786 002 2939

Fax: 0330 088 3762

Monday–Friday, 9am–5pm

POhWER

pohwer.net

01438 727192

Equality and Human Rights Commission

equalityhumanrights.com

For individual advice contact Equality Advisory and Support Service:

equalityadvisoryservice.com/app/ask

0808 800 0082

Monday to Friday 9am to 8pm and Saturday 10am to 2pm

Care Quality Commission

cqc.org.uk

CQC National Customer Service Centre,
Citygate, Gallowgate,
Newcastle upon Tyne NE1 4PA

03000 515151

enquiries@cqc.org.uk

If you are writing about treatment under the Mental Health Act, address it to 'CQC Mental Health Act'.

Review Service for Mental Health Healthcare Inspectorate Wales

Welsh Government, Rhydycar Business Park,
Merthyr Tydfil CF48 1UZ

Tel: 0300 062 8327

Fax: 0300 062 8388

Email: rsmh@wales.gsi.gov.uk

Healthwatch England

03000 583 000

healthwatch.co.uk/

enquiries@healthwatch.co.uk

National consumer champion in health and care;
contact for details of local Healthwatch

NHS Choices

nhs.uk/

Information about all aspects of the NHS including
contact for local Patient Advice and Liaison
Services (PALS).

Health in Wales

wales.nhs.uk/

Please let us know whether you have used this report and if you found it helpful.

For enquiries about this publication or feedback, please contact our Policy and Campaigns team:

020 8519 2122

action@mind.org.uk

mind.org.uk

 [@mindcharity](https://twitter.com/mindcharity)

 [mindforbettermentalhealth](https://www.facebook.com/mindforbettermentalhealth)

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