Getting it right

An easy-read campaign guide

This guide covers England, Northern Ireland and Wales

Happy  OK  In Pain  Bad

Mencap
The voice of learning disability

Getting it right when treating people with a learning disability
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What does campaign mean?

When you campaign it means you try to change things that are not working well at the moment.

What is the Getting it right campaign about?

Getting it right is a campaign to make healthcare better for people with a learning disability.

People with a learning disability should always get good healthcare from services like their doctor or local hospital.

But many people with a learning disability do not get treated properly by health services.

Some people have died because they did not get the healthcare that they needed.

It can mean that people with a learning disability die at a younger age than people without a learning disability.

Mencap thinks this is terrible and should not be allowed to happen.

We want hospitals, doctors, nurses and other healthcare staff to agree to a list of promises about how to treat people with a learning disability.

This list of promises is called a charter. There is a copy of the charter in this pack.

The charter will show them how to understand and treat people with a learning disability better.

What is this guide for?

This guide will help you campaign in your local area to make healthcare better for people with a learning disability.
The Getting it right charter

People with a learning disability have a right to the same quality of healthcare as other people.

Everyone who works in healthcare must change the way they work for people with a learning disability to make sure they get good treatment.

Everyone who works in healthcare should give good quality care and treatment.

They must agree that the lives of people with a learning disability are worth the same as other people.

By signing the charter, people who work in healthcare are saying they agree to 9 things. These things are explained on the next pages.
A hospital passport is a list of information about a person with a learning disability.

This could be

- their name, address and someone to contact if they are ill
- what kind of medicine they are taking
- any health problems they already have
- information about how they communicate – this is really important for healthcare staff when they are trying to find out what is wrong.

When a person with a learning disability goes into hospital, they can take their hospital passport with them.

The passport will help hospital staff to understand what the person needs and make the right changes to give them good care and treatment.

Not all hospital passports are the same, but you can see some examples on the Easy Health website – www.easyhealth.org.uk/healthactionplanning.aspx
Mental capacity is being able to think about and make decisions about what happens in your life.

There are laws to say when a decision can be made for someone and when it cannot.

People with a learning disability have the right to make decisions about their life, including decisions about healthcare. They should get extra support, if they need it, to make decisions.

Sometimes it may not be possible for someone to make a decision.

In this case the decision must be what is best for the person.

In England there are rules that tell healthcare staff what they must do. This is called a code of practice.

Healthcare staff must make sure the person with a learning disability gets support to have their say.
A learning disability liaison nurse is someone who is there to make sure that people with a learning disability get the support they need when they go into hospital.

Mencap wants learning disability liaison nurses in all hospitals in England, Wales and Northern Ireland.

By giving direct support to people while they are in hospital, learning disability liaison nurses can make a real difference. They can:

- help someone to feel safer and more comfortable in hospital
- help to make sure they get the right treatment and get better
- help other staff to understand what the person with a learning disability needs
- show other staff how to change the way they work to make things better for the person with a learning disability.
Lots of people with a learning disability have problems with their health. Health checks are a good chance to make sure anything that is wrong gets treated.

In Northern Ireland, people with a learning disability should get health checks every year.

In England and Wales extra money is already available for people with a learning disability to get health checks every year. But, even where there is money for the health checks, lots of people with a learning disability are not getting them.

This might be because they do not know what a health check is and how they get one, or because their doctor is not offering them.

We want every person with a learning disability over the age of 18 to be able to get a health check every year.

We want it to be easy to get a health check and we want getting a health check to be a good experience.
Learning disability awareness training teaches people about learning disability. It helps people to understand how to make things better for people with a learning disability.

Healthcare staff must change the way they work to make sure people with a learning disability get equal treatment. Learning disability awareness training will help them to do this.

We want everyone who works in healthcare to have the training. That means

- doctors
- nurses
- people who look after the building
- people who work in the hospital offices or at reception.

Carers and families of a person with a learning disability know the person very well.

They should be listened to and respected.

If the person finds it hard to communicate how they want to be treated, families and carers should be asked about the way the person wants to be treated.
Families and carers are often very close to the person with a learning disability, but they should not have to do the jobs of nurses.

It should be easy for the family or carer to stay with the person with a learning disability. They should not have to sleep on the floor or in chairs.

Hospitals and learning disability liaison nurses need to talk to local patient and carers’ groups. They should find out what services would make a difference to them.

Hospitals should make a plan about how to make things better in the future.

People with a learning disability need information in a way that is easy to understand. This means:

- signs and directions
- letters and information about their health
- information about how to take medicine.

Things like signs should be written in easy words. We call this easy read.

Many people with a learning disability do not read, so it is important that information is given to them in a way they understand.

Healthcare staff should ask them, or their families and carers, about the best way to communicate.
9. Put up the Getting it right charter and checklist for everyone to see.

The **Getting it right** checklist is a list of things that healthcare staff must do when treating a person with a learning disability.

You can see the checklist and the charter at [www.mencap.org.uk/gettingitright](http://www.mencap.org.uk/gettingitright)

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**Tom’s story**

**Tom died at the age of 20.**

He had profound and multiple learning disabilities that made it hard for him to let people know how he was feeling. Doctors and nurses did not listen to his parents when they said he was in pain. They did not give him the right treatment to deal with the illness.

Tom died of his illness, but he would not have died if he had been treated properly.
How to campaign
Here are some ways for you to take part in the campaign.

1. Sign up to support the charter

You can show your support for the campaign by telling Mencap that you agree with the charter.

To show your support fill out a Getting it right support card that is in the pack.

Send the card back to the Mencap campaigns team.

Remember, we need lots of people to support the campaign.

Ask your family and friends to sign a support card too.
2. Get people to sign the petition

A petition is something people sign to show that they support your campaign.

Anybody can sign your petition.

Try to get as many people as possible to sign your petition.

There is a **Getting it right** petition in this campaigns pack.

If you think that you will get a lot of signatures, you may want to photocopy the petition before you start getting people to sign it.

Here are 4 ways to get lots of people to sign your petition.

1. Make it easy for lots of people to find your petition. Put it on a website or email it to people.

2. Go to public places like shopping centres and train stations where you can ask lots of people to sign your petition.

3. Take your petition everywhere with you and ask people to sign it.

4. Tell your local newspaper about your petition. They may write a story about it and tell people about it.

When you have got people to sign the petition post it back to Mencap:

Freepost RRKL-SRXZ-RTKY
Mencap campaigns team
123 Golden Lane
London EC1Y 0RT

Always make sure that you keep a copy of your petition.
3. Tell your local healthcare authority what you think

Your local healthcare authority is the group of people who make decisions about health services in your area.

You may want to write to your local healthcare authority.

England, Northern Ireland and Wales have different names for these authorities.

- In England **primary care trusts** are in charge of the healthcare services.
- In Northern Ireland **health and social care trusts** are in charge of the healthcare services.
- In Wales **local health boards** are in charge of the healthcare services.

Here are some things you can put in the letter

1. Tell them about Mencap’s **Getting it right** campaign

2. Tell them why the campaign is important to you. You may want to tell them that you have a learning disability.

3. If you have had a bad time with your healthcare you may want to tell them about it.

4. Put your name and address in the letter so that they can write back to you.

5. If you are having an event you may want to invite them.
4. Make posters and leaflets

Tell other people what you think by handing out leaflets or posters.

Posters and leaflets are also a good way of telling people about a meeting or petition.

You can use the Getting it right posters and leaflets in this pack. Or you can make your own.

A good poster tells people
• what your campaign is about
• what is happening to the people you are campaigning for
• how to join the campaign
• how to get more information.

Put the poster somewhere where lots of people can see it.

A good leaflet tells people
• about your campaign
• what you want to do
• how they can join your campaign
• who wrote the leaflet.

Leaflets should be short and easy to read.

5. Get the media involved

When we talk about the media we mean newspapers, TV and radio.

If you want lots of people to know about your campaign tell the media.

You can tell the media about your campaign by writing a press release. A press release is a story you send to the media to tell them about your campaign.

There is an example of a press release in this pack. You can look at this to help you write your press release.
Here are some things to remember when writing a press release.

- Think about what you want to say.
- Keep it short.
- Put the most important information first.
- Include quotes from important people like your MP in England, MLA in Northern Ireland or AM in Wales.
- Make sure you are allowed to use quotes.
- Put your contact details on the press release.

A quote is something someone has said.

Send your press release to your local media.

You can find out where to send your press release by
- visiting www.mysociety.org to find the names of local newspapers
- calling the newspaper and asking to speak to the news desk.

Call the person you have sent the press release to ask them if they would like more information.

Top tips to get the media interested

Use stories about real people.

Get a local celebrity to support the campaign.

Talk about healthcare in your local area.

Think about the best time to send your press release. If you are having an event, send a press release 1 week before.

Offer them someone they could interview. For example you might know someone who has a story to tell about healthcare and will be happy to talk to the media.

Send good pictures of people who are taking part in the campaign. For example a photo of a group of people standing outside a hospital.
If you would like some help with getting the media involved contact the media team. Remember, we are here to help and give advice if you need it.

- In England call 020 7696 5414
- In Northern Ireland call 028 9069 1351
- In Wales call 02920 747 588

Or send them an email to media@mencap.org.uk

6. Have a public event

One of the best ways to show how many people support your campaign is to have a public event.

Set up a stall on the street
A stall is a great way to tell people about your campaign.

It must be in a place where lots of people will see you.

For example
- shopping centres
- train stations
- local football stadiums.

You might need permission for this.

Have a public meeting
Get everyone together to talk about your campaign.

It is useful to have a public meeting about your campaign if

- you do not have much money to spend
- you do not have much time
- you know lots of people want to know more.
7. Use the internet

You can use the internet to tell people about your campaign. This is called e-campaigning.

E-campaigning can work really well when you do not have a lot of money to spend.

If you want to make sure people know about your campaign there are 3 things that you can do using the internet.

Send emails about your campaign

With emails you can tell people about your campaigning, meetings and petitions.

Emails are good because they are quick and you do not need to spend money on posting.

You must check your email every day.

Get a website for your campaign

A website is a great way to give more information about your campaign.

But websites can cost a lot of money and can be difficult to run.

Before you set up a website do your research.

Make sure you

- speak to other local groups who have websites
- contact your community development officer (CDO) if you live in England
- contact your support and development worker if you live in Northern Ireland
- contact your district support officer if you live in Wales
- find websites you like.

Go to www.mencap.org.uk to see how a website could look.
Join a social networking site

A social networking site is a website where people can talk to each other and share things like photos, ideas and events.

Facebook, Bebo, MySpace and Twitter are all social networking sites.

You can set up your own webpage on these sites to tell people about your campaign.

The webpage will help you to

- find people who want to join your campaign
- tell people about a meeting
- raise money for your campaign.

Go to www.twitter.com/mencap_charity to see how a webpage could look.

Remember: e-campaigning should be used as well as other ways of campaigning because not everyone has access to the internet.

Speak to us

Please tell us about the things you are doing to campaign in your local area.

Mencap’s campaigns team are happy to help!

- If you live in England contact your community development officer (CDO).
- If you live in Northern Ireland contact your support and development worker.
- If you live in Wales contact your district support officer.
Mencap would like to thank Jim Blair, Joanne Bratchell and St George’s Healthcare NHS Trust for their help and support.
If you live in England

📞 Phone: 020 7696 5613  
✉️ Email: campaigns@mencap.org.uk  
✉️ Write: Mencap, 123 Golden Lane  
         London EC1Y 0RT

If you live in Northern Ireland

📞 Phone: 028 9069 1351  
✉️ Email: mencapni@mencap.org.uk  
✉️ Write: Mencap, Segal House  
         4 Annadale Avenue  
         Belfast BT7 3JH

If you live in Wales

📞 Phone: 029 2074 7588  
✉️ Email: information.wales@mencap.org.uk  
✉️ Write: Mencap Cymru  
         31 Lambourne Crescent  
         Cardiff Business Park  
         Llanishen, Cardiff CF14 5GF