

Easy  
Read

# Independence Pack



*Helping you to move out of your inpatient  
unit and into your community*



# Independence Pack



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*Produced with the support of NHS England, Local  
Government Association, and ADASS, the Association of  
Directors of Adult Social Services*

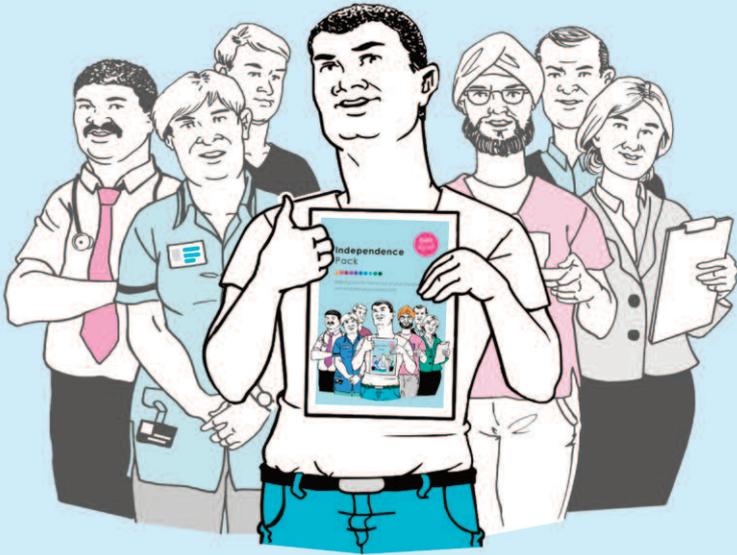
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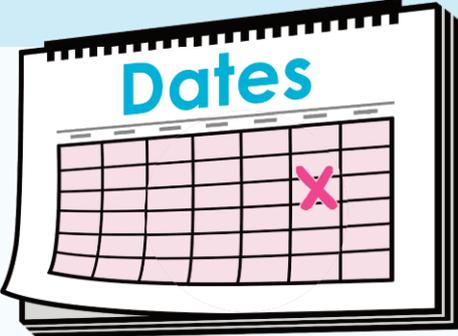
We would like to say a special **thank you** to the following people and organisations:

*Andrew Bainbridge - Cornwall People First, Beyond Limits, Plymouth Care Quality Commission, The Challenging Behaviour Foundation, CHANGE Words to Pictures Team, Choice Support Consortium Experts by Experience, Daniel Gower, Darlington People's Parliament, Disability Sheffield, Erin Outram, Gavin Harding MBE, Helen Cherry, Jane Pritchard - TV Edwards LLP, Jez Buffin - University of Central Lancashire, Jez Coram, Kaleidoscope – Changing Perspectives, Changing Lives, Kenneth Fletcher, London Social Care Partnership, Lumos, Mencap, Neil Crowther, NHS England, POhWER Self-advocacy group - Hackney, Respond UK, Sara Ryan, Speak Easy N.O.W., Speak Up Self – Advocacy, Sunderland Carers Centre, VoiceAbility*





My pack  
was last  
reviewed  
on:



- 1 \_\_\_\_\_
- 2 \_\_\_\_\_
- 3 \_\_\_\_\_
- 4 \_\_\_\_\_
- 5 \_\_\_\_\_
- 6 \_\_\_\_\_



**My steps  
for moving  
home**

*You can use these pages to plan important steps. This might be things like filling in an application form to rent a flat or advertising for staff to support you.*

**Date:**

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**Tick when done:**

**Step:**

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**Date:**

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**Tick when done:**

**Step:**

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Date:

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Tick when done:

Step:

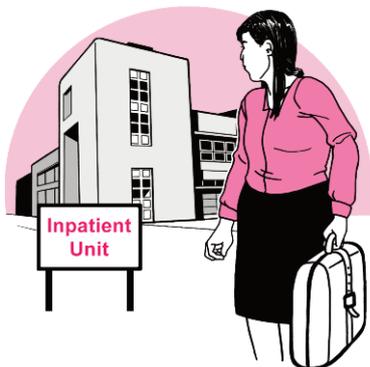
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**What is this  
pack about?**



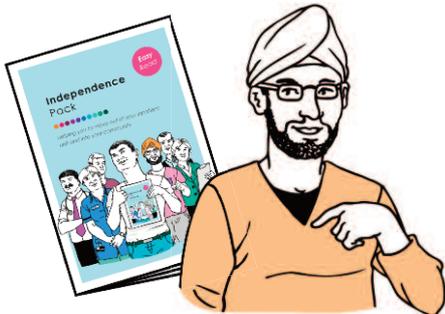
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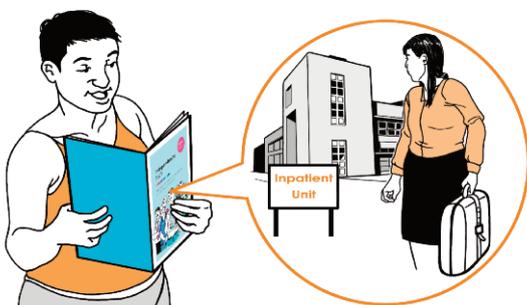
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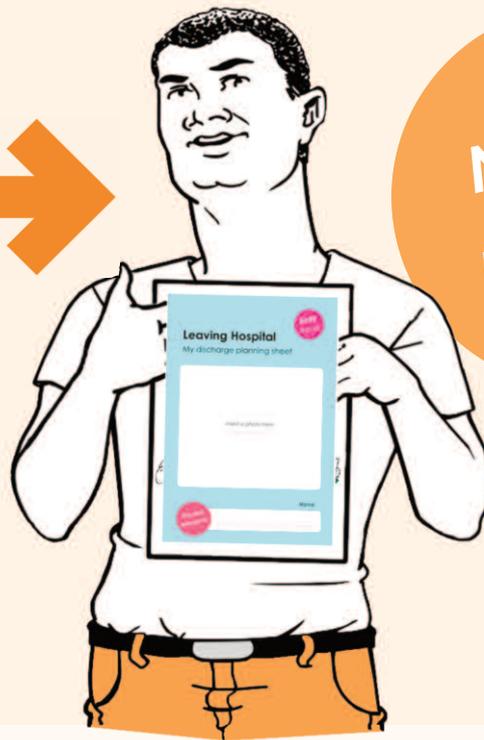
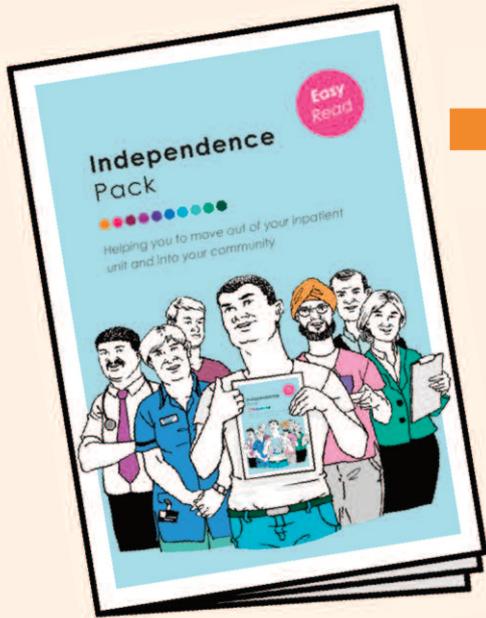
**15** This pack belongs to



**18** My Medication and treatment



**19** What this pack is about



Note to patients

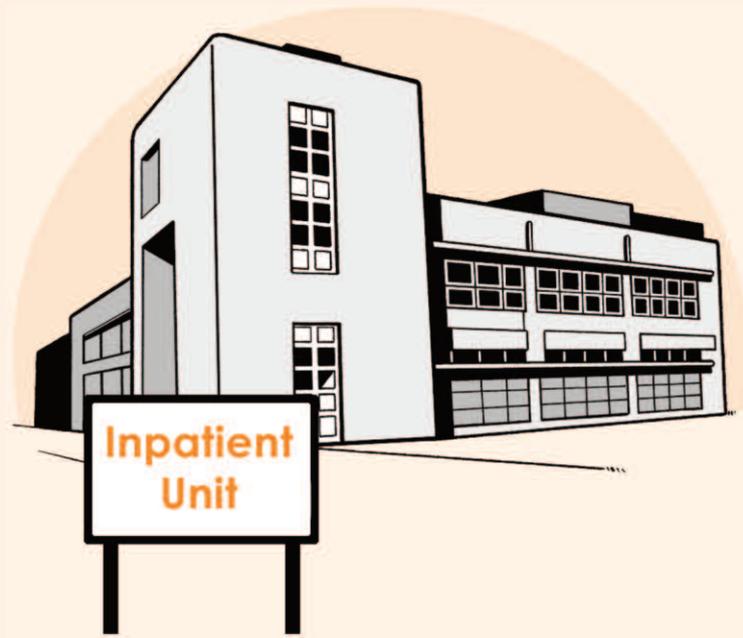
This is a pack for you to keep.



The pack supports the Discharge Planner called Leaving Hospital and is for people with learning disabilities or autism who are in inpatient settings.



This pack helps people think about moving out of inpatient units and into the community.



**Inpatient units** are types of hospitals for people who have mental health conditions or behaviour that can be challenging.



This pack will help you to get ready for leaving an inpatient unit.



It will also let you know what your rights are, how to make choices about your care, and how you can get help if you are not happy.



In the pack there are spaces for you to write information about yourself and any thoughts or questions you may have. These spaces are white boxes with dashed lines.



All of the materials you need are on the memory stick in your pack, or they can be downloaded from [www.changepeople.org](http://www.changepeople.org).



## Note to Staff, Advocates and Carers

The aim of this pack is to prepare patients for leaving inpatient units. This book belongs to the patient and there are sections which are to be completed by the patient with support.

The pack has been designed using an easy read format so that it is more accessible for patients with learning disabilities. Some patients will need help in reading the pack and filling out the sections.

The pack also contains local information sections. It is important that these are completed to allow patients to fully prepare for discharge.

The pack should be part of a range of support for preparing patients for changes and moving back into the community.

This pack belongs to:

Name

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What I like

-----  
-----  
-----  
-----  
-----

About me



What I dislike

-----  
-----  
-----  
-----  
-----



What I'm good at

-----  
-----  
-----  
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About me



Favourite foods

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-----  
-----  
-----  
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Food I dislike

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-----  
-----  
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Family/friends

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What support I need

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# About me



## How to communicate with me

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## My future plans

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## My hopes for the future

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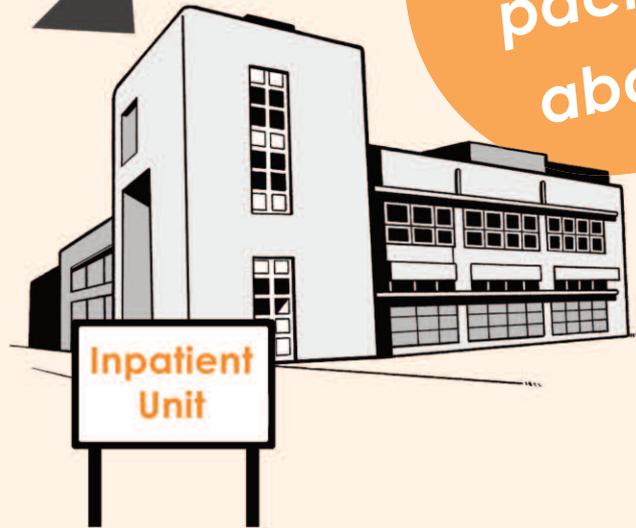
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# Medication and Treatment

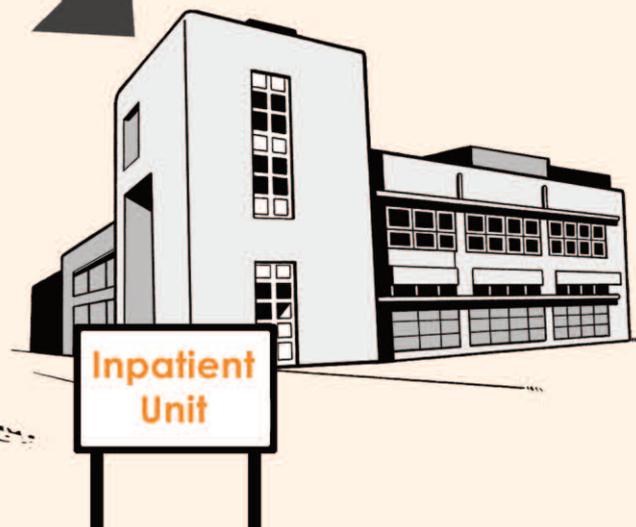


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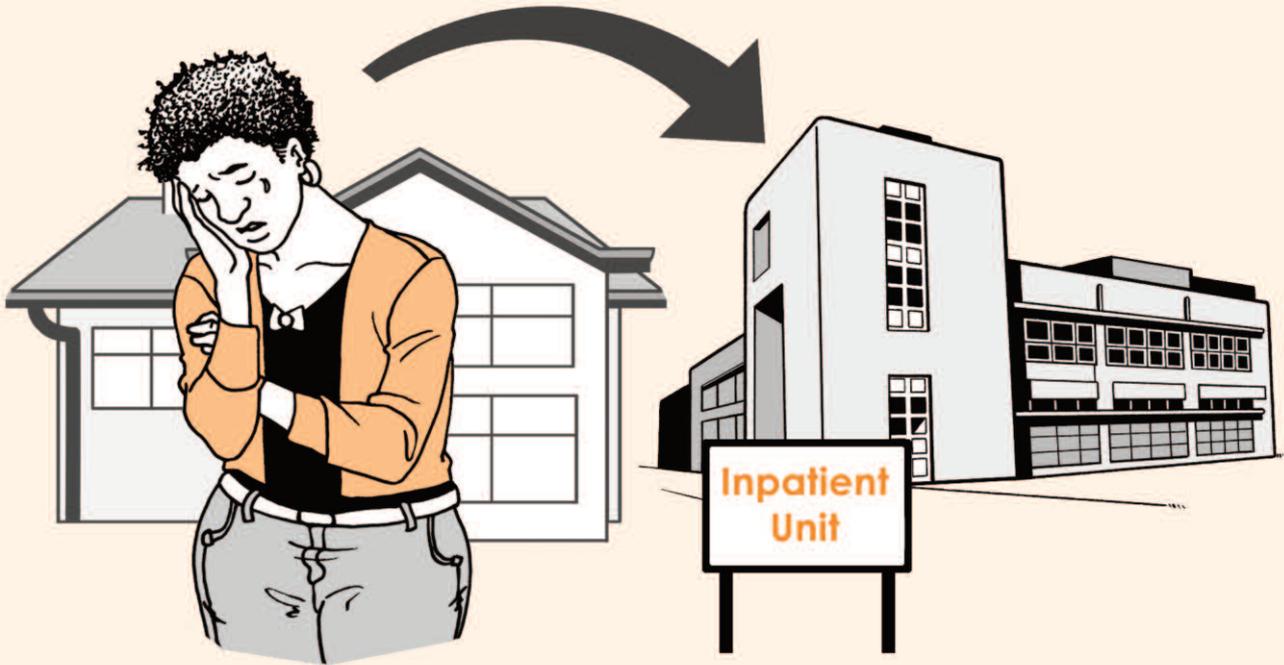
What this pack is about



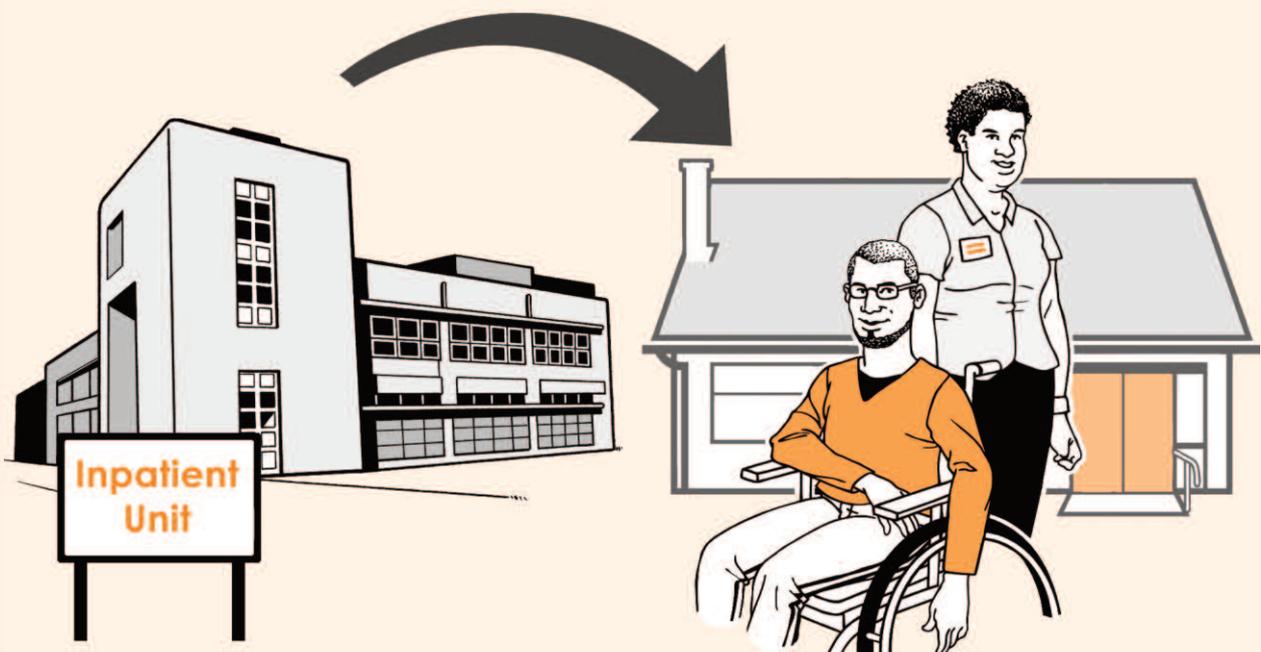
Sometimes people with learning disabilities or autism may be admitted to an **Assessment and Treatment Unit**, which is like a small hospital.



Sometimes people go to assessment and treatment units when they need extra support.



Sometimes people go if they are in danger of hurting themselves or other people and they can't get the right support or treatment at home.



You will only stay in an inpatient unit as long as you need to, then you will get support at home.



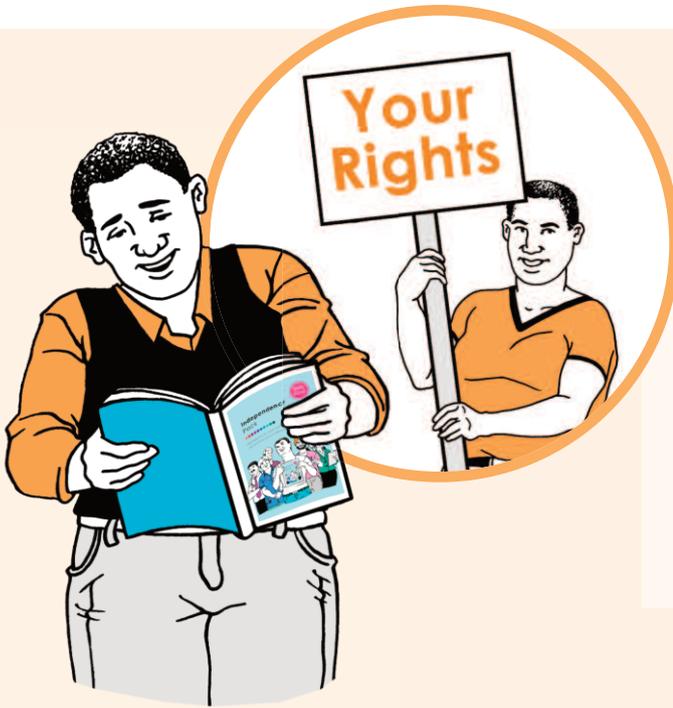
When you and the inpatient unit feel you are ready, you will leave the inpatient unit, this is called being **discharged**.



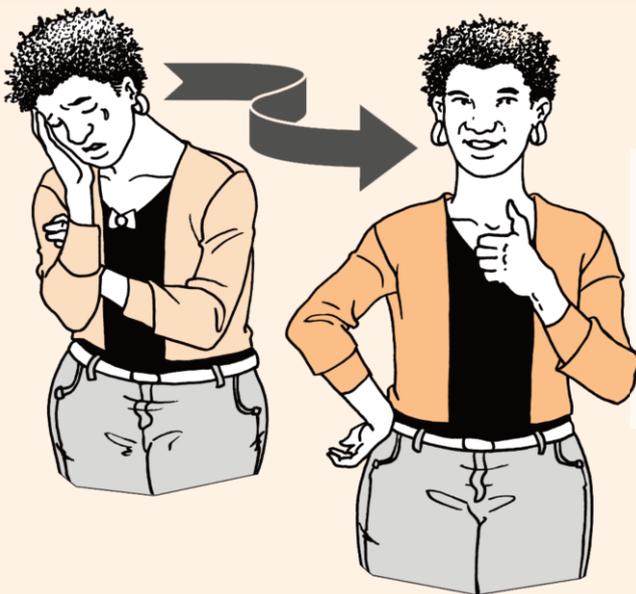
You may move back to where you lived before, or move somewhere new with the right support.

This pack is to help you to get ready for leaving an inpatient unit.





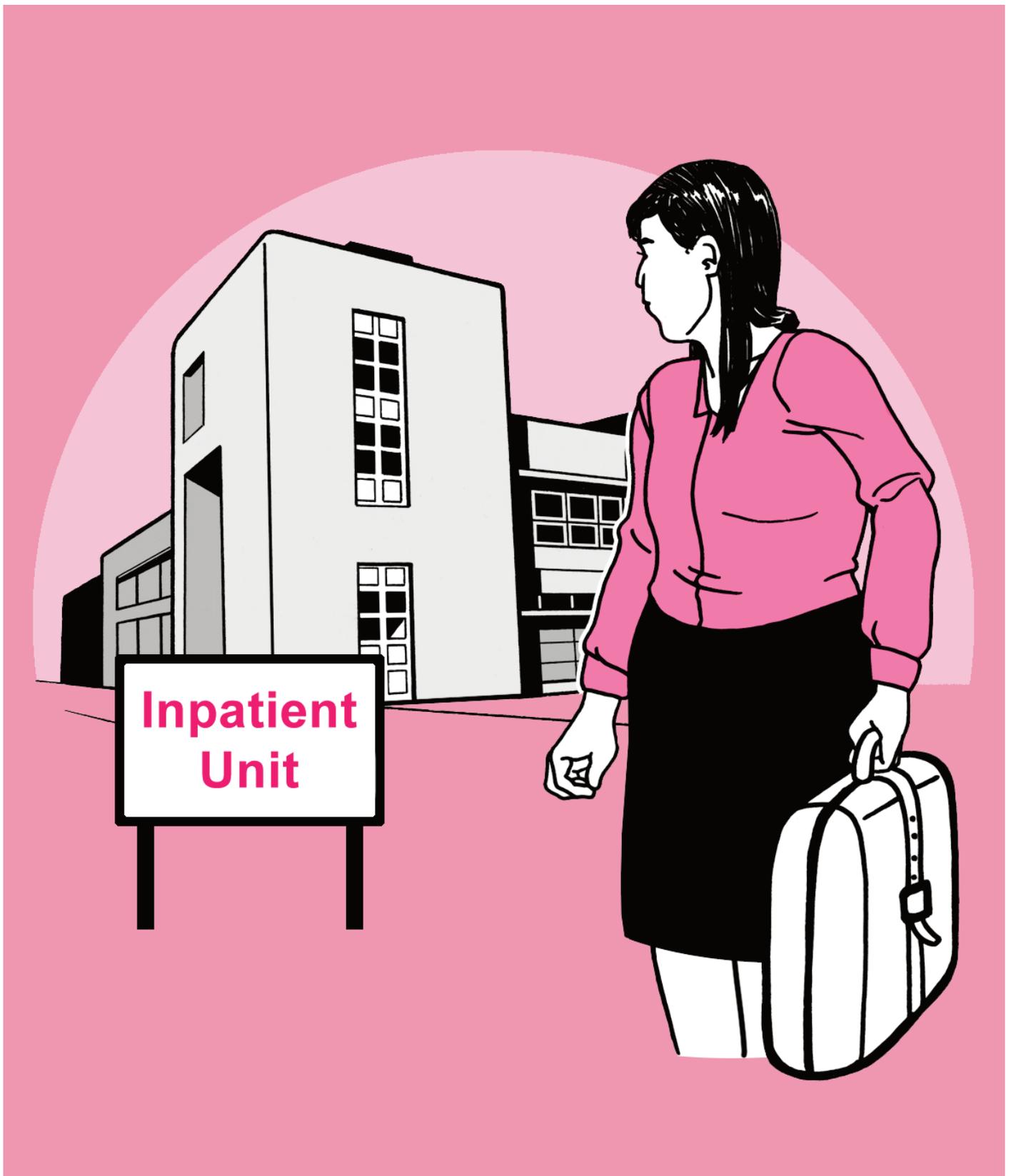
It will help you know what your rights are now and when you leave your inpatient unit.



It will let you know what to do if you are not happy.



This pack will also help you to find activities to do in the community once you leave the inpatient unit.

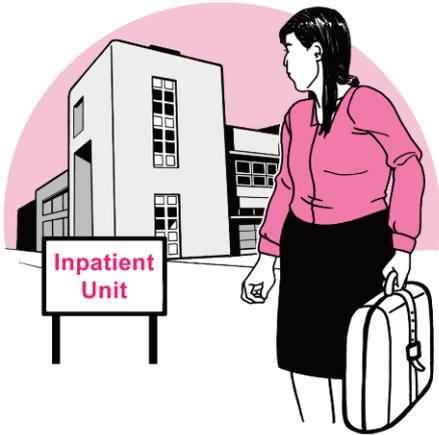


**When will I be  
discharged?**



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When will I be discharged? - contents



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When will I leave the inpatient unit?



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What should a discharge plan look like?



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I am not happy with my discharge plan, what should I do?



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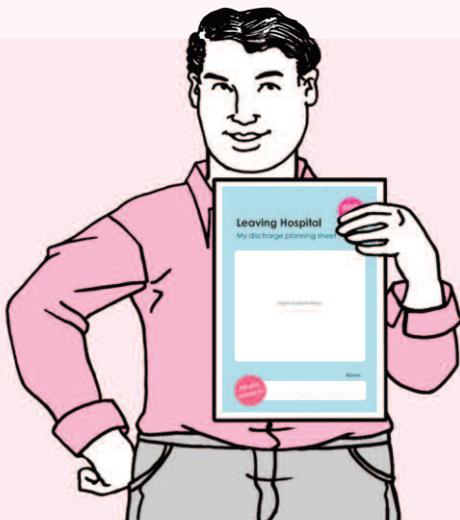
The Care Programme Approach and Reviews

When  
will I leave  
the inpatient  
unit?

I am leaving the inpatient unit  
on:



When you go to the inpatient unit the staff will work with you to make a plan for what will happen when you leave.



This is called a **discharge plan**.

# Your discharge plan is about:



Where you will live.

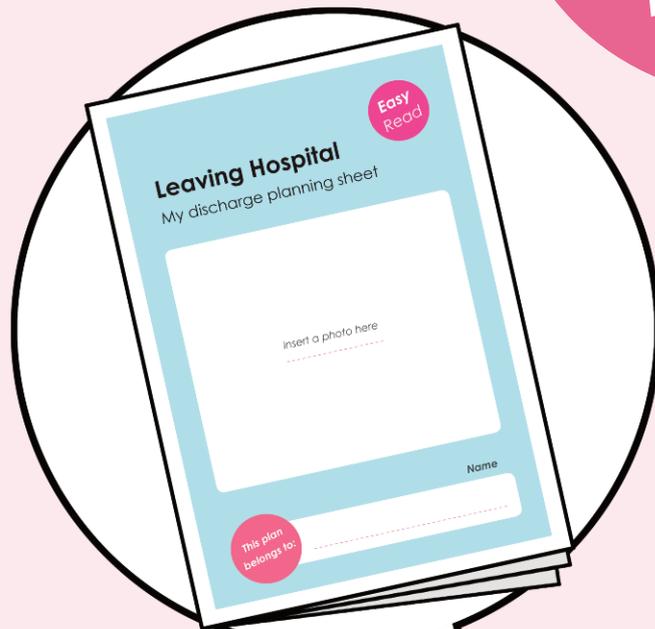


What you will do each day.



The support you will need and how you will get it.

What should a discharge plan look like?

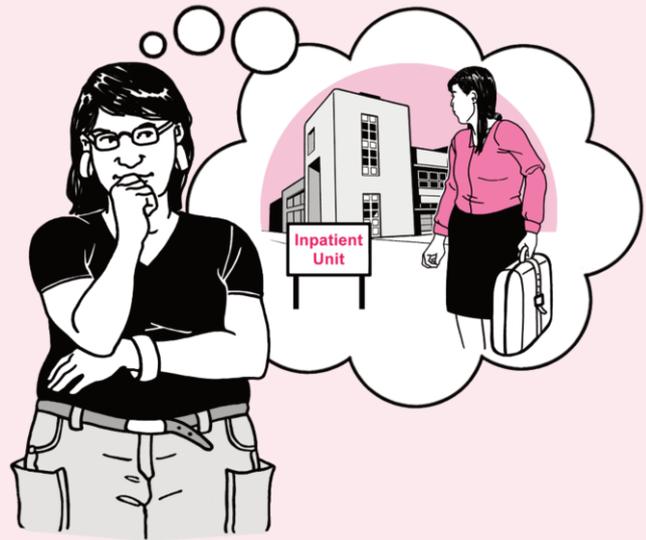


It is really important that staff work with you to make your discharge plan straight away.

# There are certain things that a good discharge plan should include:



An **All about me** section with what you like and dislike.



What you would like when you leave the inpatient unit.



Where you will live when you leave the unit.



What you will do each day when you leave, and who will help you.



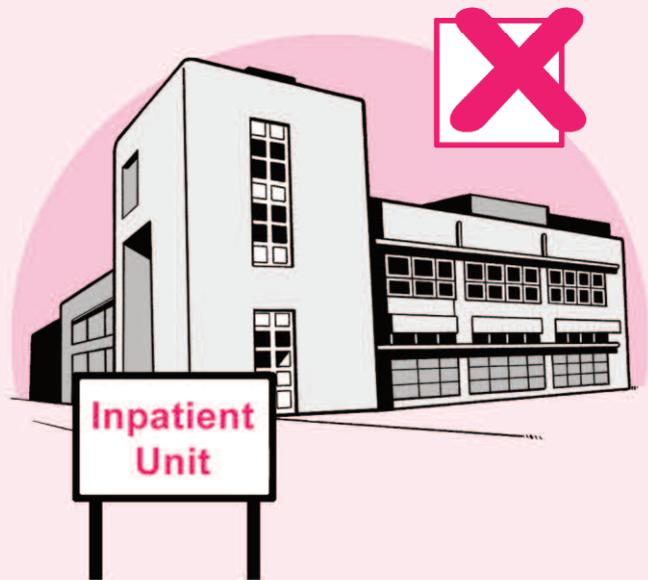
What will happen to help you get new skills.



What will happen to help you make new friends.



What will happen to help support your health and wellbeing.



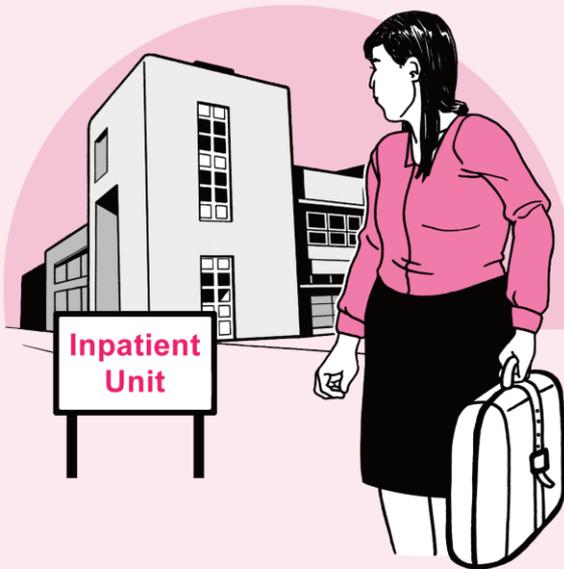
What will happen to help make sure you do not have to go back to the unit.



What will happen to support you with your hobbies and interests.



What will happen about your money and belongings.



The things that will happen to support you to get ready to leave the unit.



How you will be involved with your family and how your family will be supported.



I am not happy with my discharge plan, what should I do?

If you are not happy with your discharge plan, or if you don't have one you can speak to the following people:



**Your Doctor  
(at the unit)**

**Your  
advocate**

**A family  
member or  
carer**

**Care  
navigator**



## The Care Programme Approach and Reviews

When you are in the unit you may hear people talking about the **Care Programme Approach** (CPA).



This is a way of planning and reviewing your needs to make sure that your treatment, care and support works well together.



## Care Programme

**Approach** means that there is a written care plan which has details of any risks and what to do in an emergency or crisis.



You will have a **Care Programme Approach Coordinator** (care-coordinator) who will make sure that assessment, planning and review happen.



You should be given their contact details.

What will a  
CPA meeting  
be like?



A **Care Programme Approach** meeting can be run by anyone in the unit, including you.



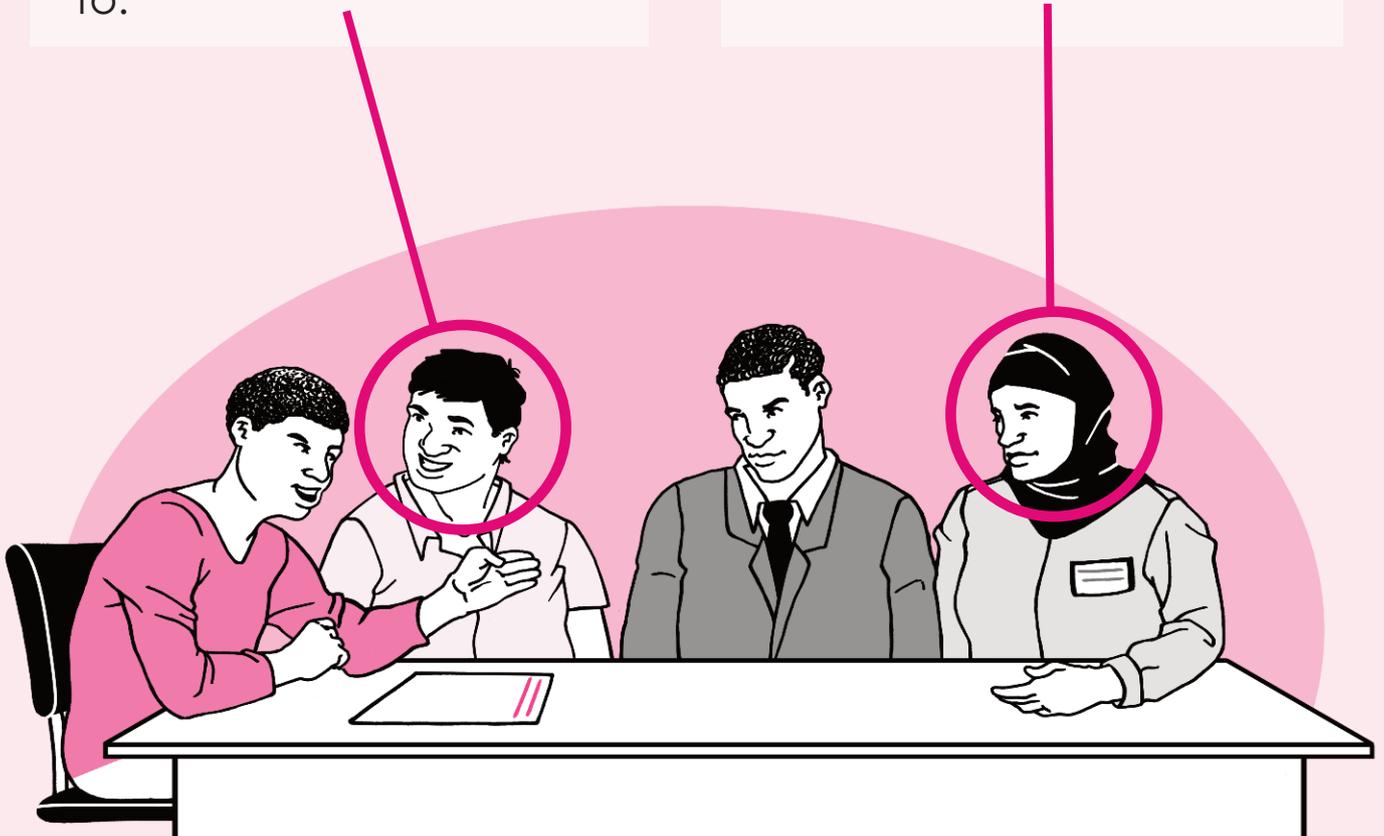
People should make you feel welcome and comfortable.



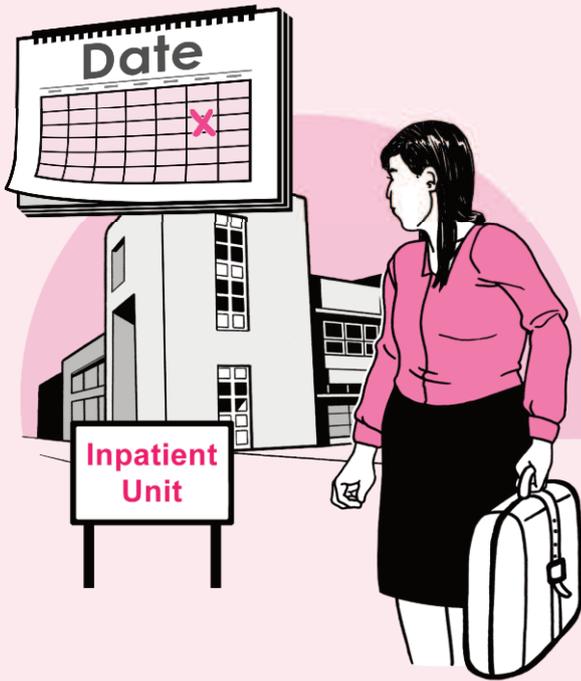
You should be introduced to everyone at the start.

Your **advocate** should come to your meeting with you if you want them to.

Your **care-navigator** from the community should also be at the meeting.



The plan for your treatment and care should be the focus of the meeting.



The date you will leave the unit and what needs to be done to get you ready for leaving the unit should be talked about at every meeting.



This is your meeting and it is your right to be involved and listened to. Ask the questions you want to ask, and don't feel that you can't.

**My views  
for the meeting  
are...**



You do not have to go to your meeting, however it is important that you let staff know your views so that they can be given at the meeting.



What will my  
CPA plan  
look like?

As part of the meetings you and the unit will make a plan.

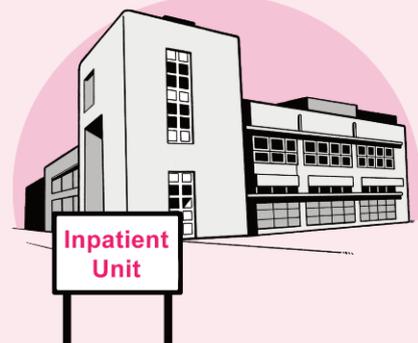
**This should include the following things:**



**Your basic  
details**



**Who supports  
you in the unit  
and in the  
community**



**The reason  
you are in  
the unit**



It will also include whether you agree to any treatment, and if you cannot make that decision yourself, it will have details of who will make that decision for you.



An **All about me** section to help people understand you, how to support you and what you like and dislike.



Why you need **treatment**, what it is and how it will help you.



Any risks to you and to others.



Your treatment plan and how often it will be reviewed.



Activities you will do while you are in the unit.



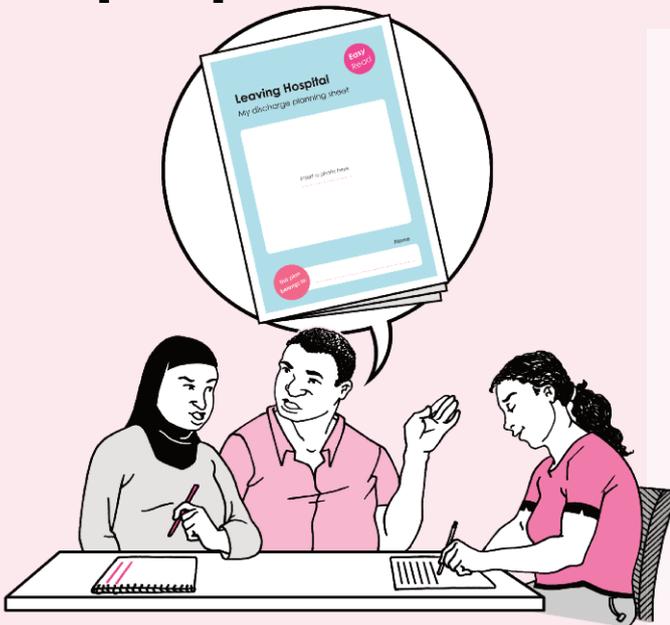
How you will keep in touch with your friends and family in the community while you are in the unit.



The plans for your **Care Programme Approach** review meetings.



Very often people with learning disabilities stay in the units for too long.



It is important that you make sure your discharge plans are looked at regularly, and challenge your detention if you think you no longer need to be in the unit.



You can ask your advocate or a family member or carer to help you do this.



Where will  
I live?



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Where will i live?



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Living at home  
(with family and  
independently)



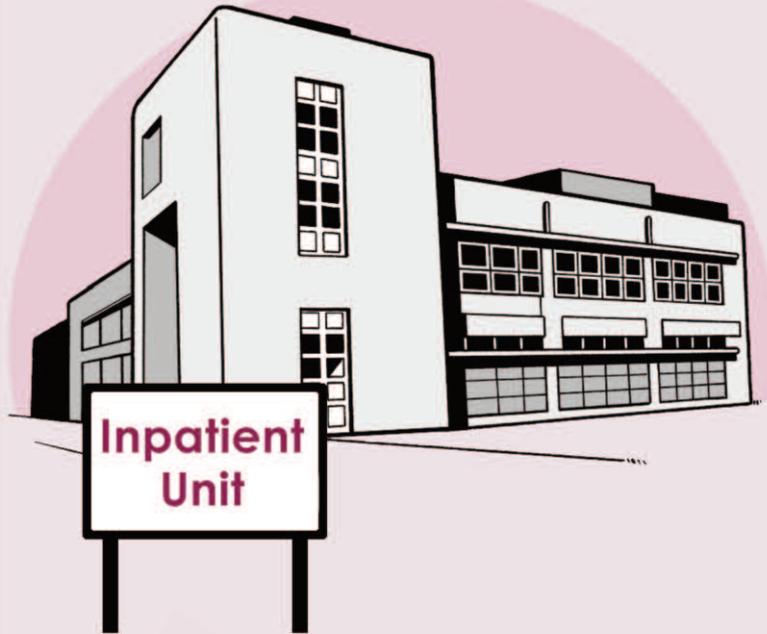
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Care home



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Supported living



Where  
will I live?



You should be involved in deciding where you want to live and where your new home should be. There are different options of where you might move to after you leave the unit.

You may go back to where you lived before you came to the unit or you might move somewhere new.



It is important that you get the chance to visit your new home before you leave the unit.



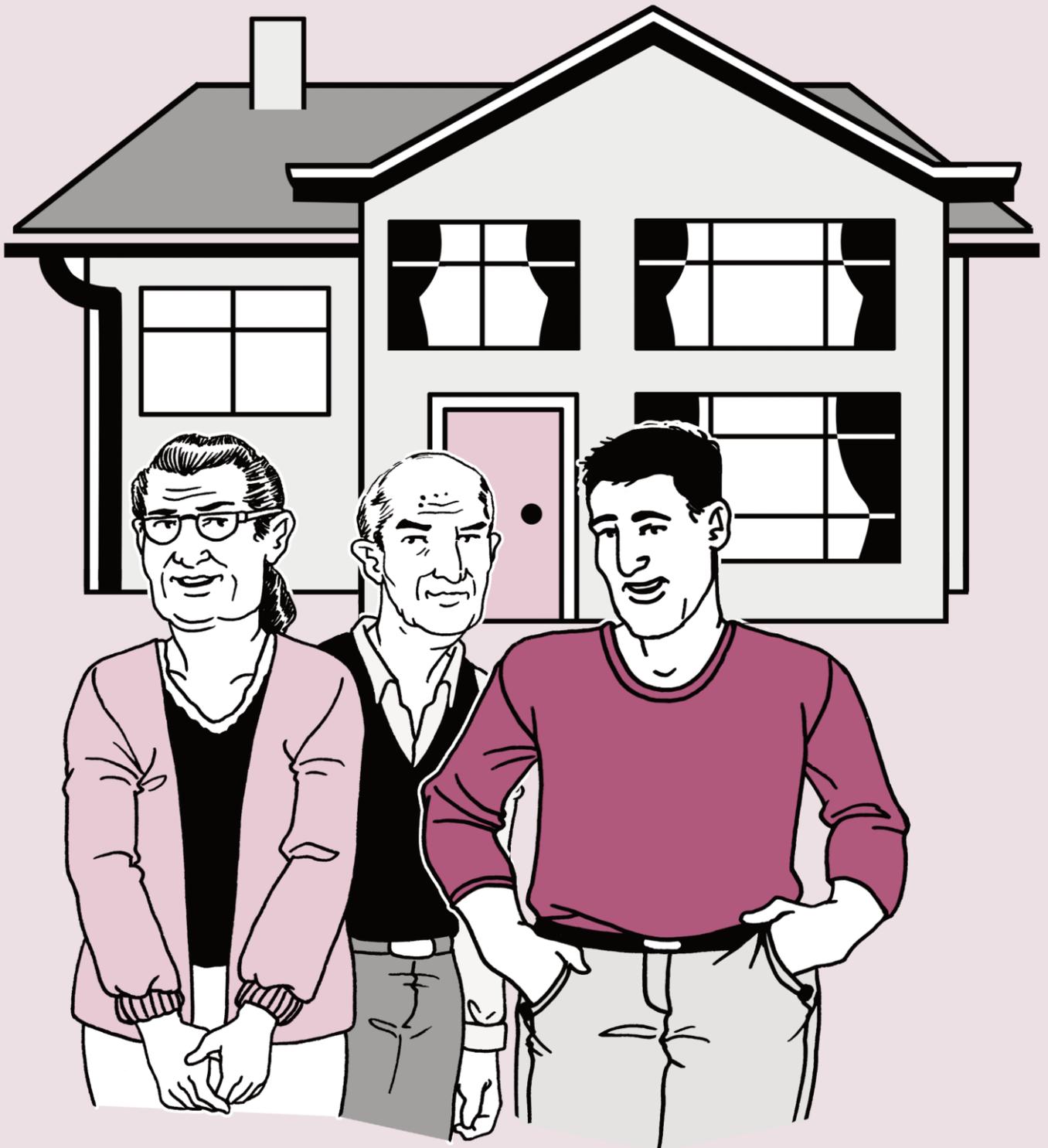
You should ask a member of staff to arrange this for you if you do not already have a visiting date.



If it is not possible for you to visit your new home before you leave, you can ask a staff member or your carer to bring some photographs of your new home which you can put into this book.

Living at  
home with  
family

Some people might live back at home with their family after they leave the unit.

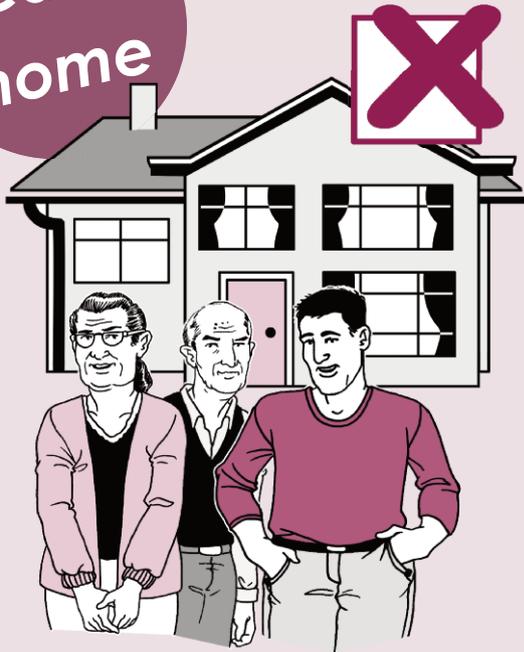


## Living at home independently

Some people might live at home **independently** after they leave the unit. They may have some support but living independently means that you can make your own choices.

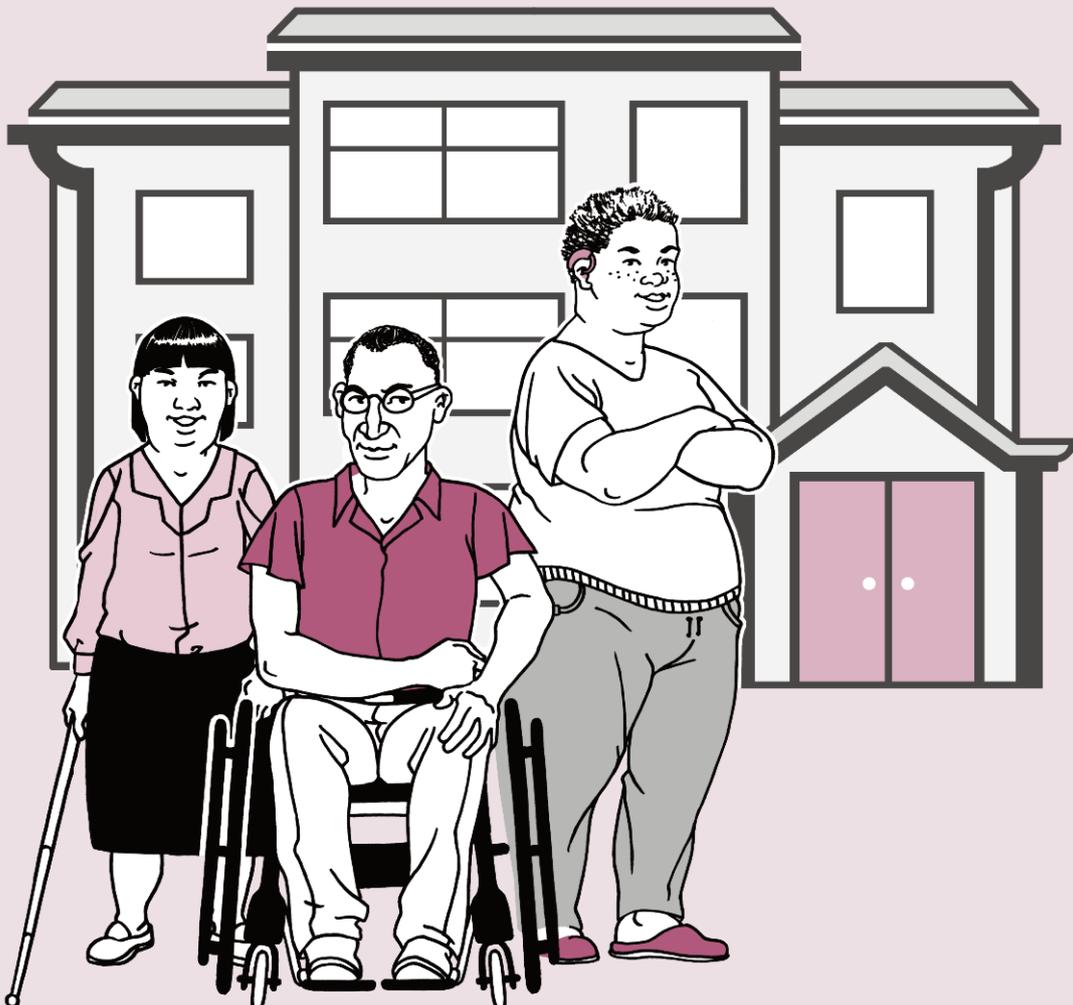


Care  
home



Some people will not be able to live with their families **or may not want to**. It is not always possible for them to live in the same place.

Some people might go and live in a care home.





In a care home you will live with other people with similar needs to you.

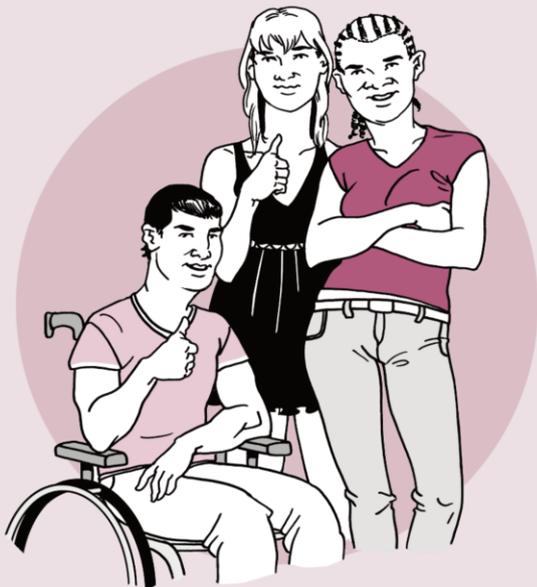
There will be staff and carers who work at the home and help give you the support that you need.



# Supported Living



You may go and live in something called supported living.



You may live on your own or with one or two other people.



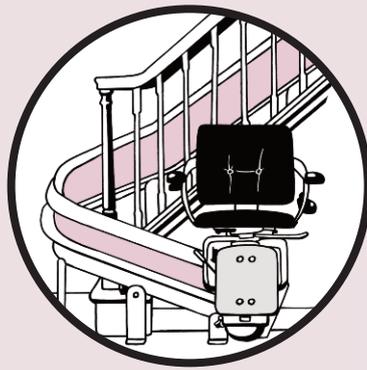
You will have staff in your home to help you with daily tasks and give you any support that you need.

*Things I would like  
to know about my  
new home...*



A large white rectangular area containing ten horizontal dashed lines, intended for writing.

*What I need to support me in my new home...*



A large white rectangular area containing ten horizontal dashed lines for writing.

*I am moving to...*

Space  
for photos



*I am moving to...*

Space  
for photos



*I am moving to...*

Space  
for photos





## Getting help from an advocate



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Getting help from an advocate - contents



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What is an advocate?



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Types of advocate



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When you leave the unit



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Self advocacy groups



## What is an advocate?

While you are in the unit and after you leave, you can have an **advocate**.



An **advocate** is an independent person who helps you have your voice heard and makes sure that your views and wishes are listened to when decisions are being made about you.



An **advocate** will talk to you to find out what you want and how you feel.

They will listen to you and can talk to other people for you.



An advocate can help you say what you think about your mental health care or treatment.



What you  
need to  
know

**Advocates** do not work for social services or the NHS. This means they can support you to have a say if you are not happy with your care.



**Your advocate will only talk to other people:**



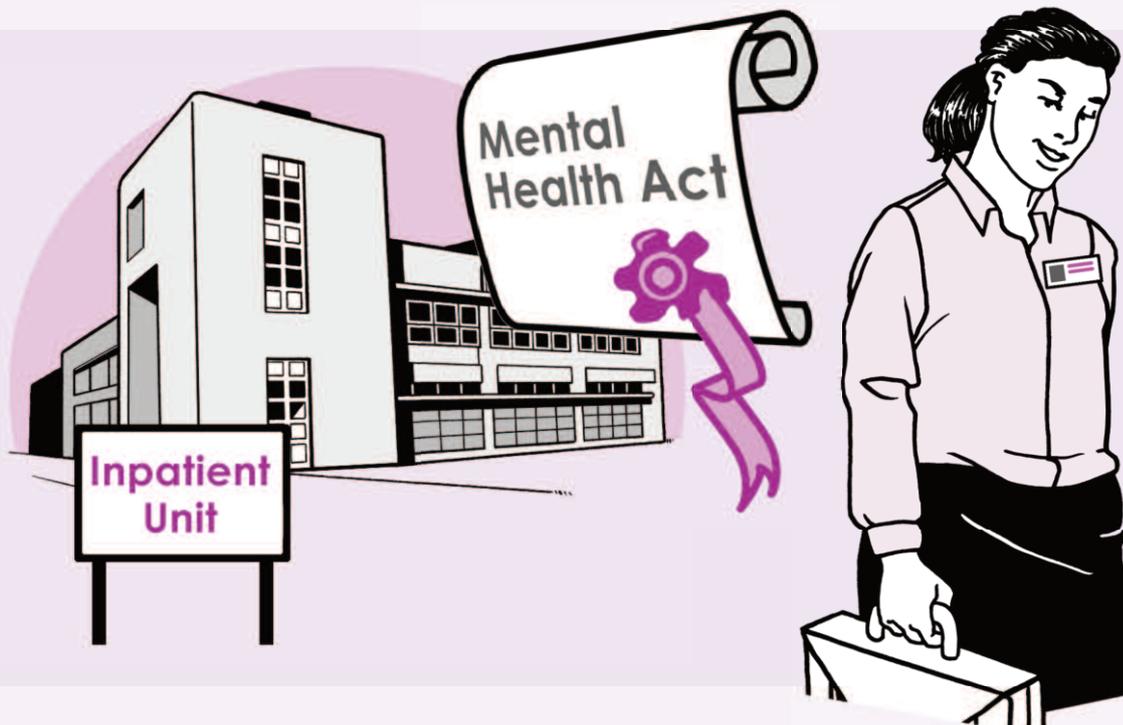
When you want them to.



Or if you or someone you know might get hurt.



Sometimes **advocates** might have different names but they are all there to help you make sure that your voice is heard.

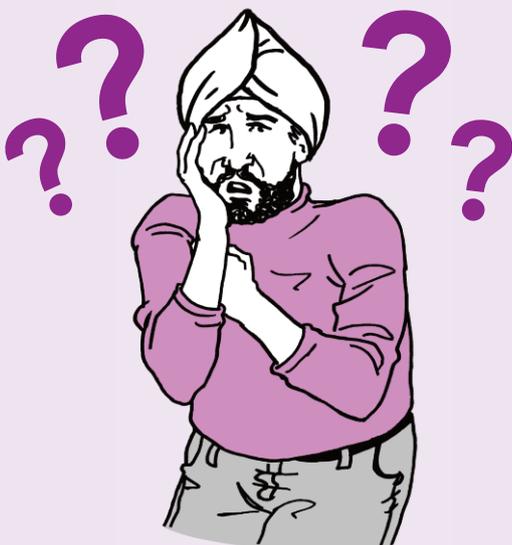


While you are in the unit you might have an **Independent Mental Health Advocate (IMHA)** if you are being kept in the unit under the Mental Health Act.

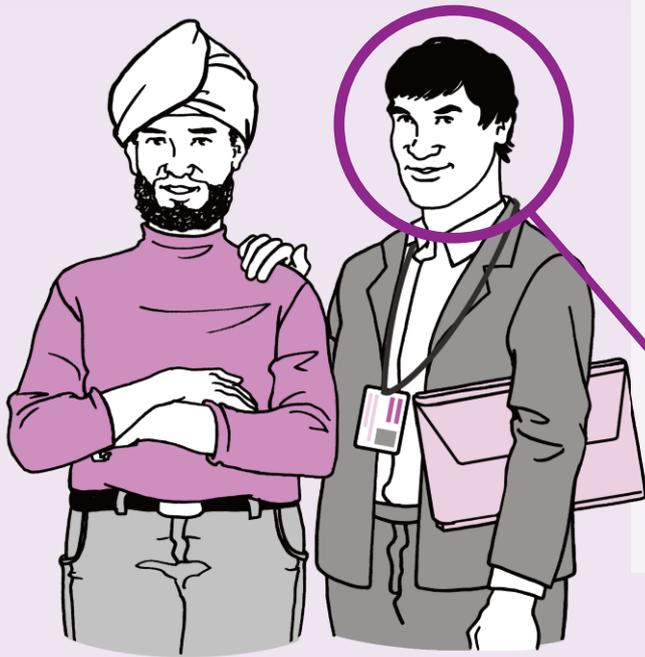


An **Independent Mental Health Advocate (IMHA)** can help you find out about your rights in the unit as well as powers being used by professionals involved in your care.

An **Independent Mental Health Advocate (IMHA)** can also come to meetings with you and help you solve any problems you have with staff or services in the unit.



Sometimes people are unable to make decisions about their care or treatment. This is called **lacking capacity**.



If you are unable to make decisions about your treatment or care and a decision has to be made about your treatment you can have an **Independent Mental Capacity Advocate (IMCA)**.

An **Independent Mental Capacity Advocate (IMCA)** can help support you and make your wishes and feelings known and can challenge decision makers on your behalf.





When you  
leave  
the unit



You can also have an **advocate** when you leave the unit.



An **advocate** can help you find the right support, this might be with activities or problems with housing.

An **advocate** can also support you at meetings with health and social care professionals.





If you would like an **advocate** you can **ask a member of staff** or a **family member** to arrange for an advocate to come and see you **or you can ring** your local advocacy service and arrange a meeting.



My local  
advocacy  
service is:

-----



## Self advocacy groups

You could join a **self-advocacy group** which will help you to build your confidence, become more empowered and get peer to peer support from other people with similar experiences to you.



**Self-advocacy groups** are also a great way of meeting new people and learning new skills so that you can stand up for your rights.



You can speak to your advocate to find out when your local group meets.



**Who will  
support me?**



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Who will support me?  
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Who will support me



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Social Worker and  
Care-Coordinator



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Carer and  
Housing support worker



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Counsellor or  
Psychologist,  
Psychiatrist, Community  
Learning Disability  
Nurse

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Who  
will support  
me?



When you are discharged from the unit lots of different people will give you the support you need. These may be professionals, your family and other people with learning disabilities and autism.

## Social Worker



## Care-Coordinator



A **social worker** is a person who will come and visit you in the community and make sure you have everything you need and that you are safe.

You may also have a **care-coordinator**. It is their job to bring together all the support you might need to live well in the community.

## Carer



## Housing support worker



You may live with your **carer** or you may have carers that come to your home and support you. Your carer will help to support you in your daily life.

If you move to supported living you may have a **housing support worker**. They can help you with any problems you have with your housing.

## Counsellor or Psychologist



You may have a **counsellor or psychologist** who will help you talk about your problems and help you learn how to deal with them.

## Psychiatrist



You may also have a psychiatrist. This is a type of doctor who helps to treat Mental Health Conditions. They can give you medication and treatment. They might give you treatment while you are in an inpatient unit or while you're in the community.

## Community Learning Disability Nurse



A community learning disability nurse may support you after you leave the inpatient unit. They will help you to keep healthy and access the health services you need so that you can lead an independent life.



**What are  
my rights?**



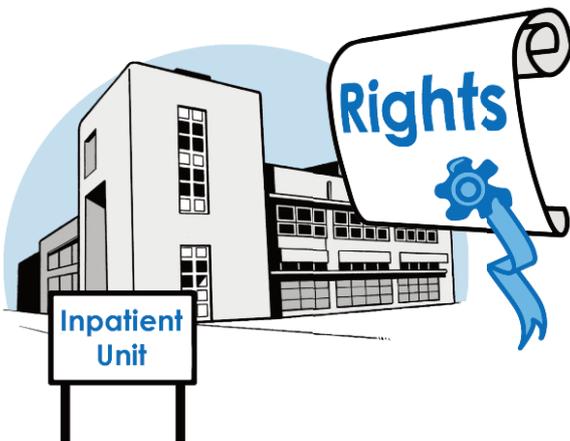
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What are my rights?  
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What are  
human rights?



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What are my rights in  
the unit?

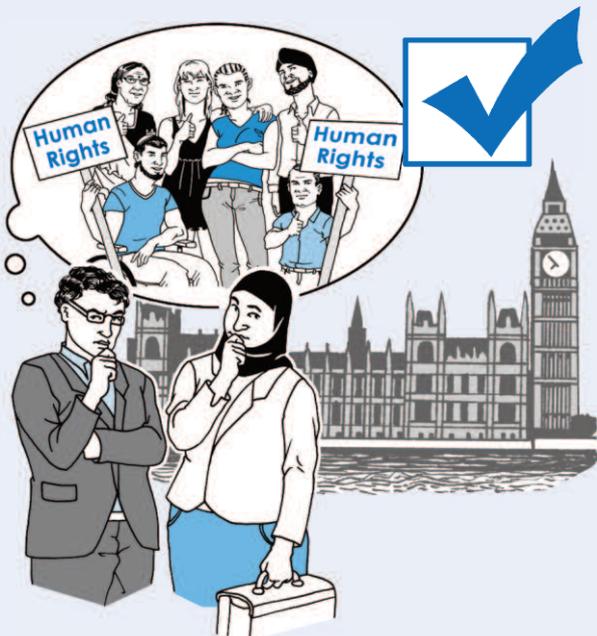


100

What are my rights  
when I leave the unit?



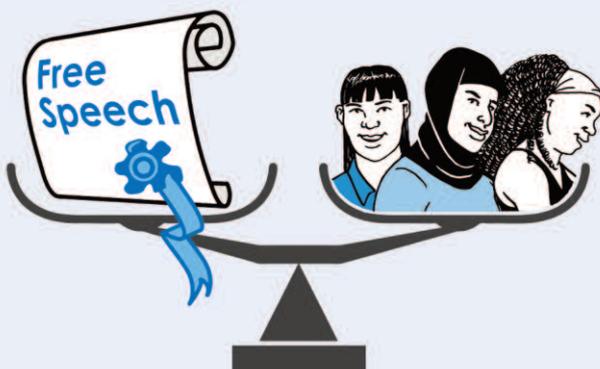
## What are human rights?



A **right** is something you are allowed to do. The Government and all your public services must respect your rights.



Some rights, like the right to life can never be taken away.



Other rights, like the right to free speech, might have to be balanced because of the rights of others.



You have a number of rights which are protected by something called the **European Convention on Human Rights**.



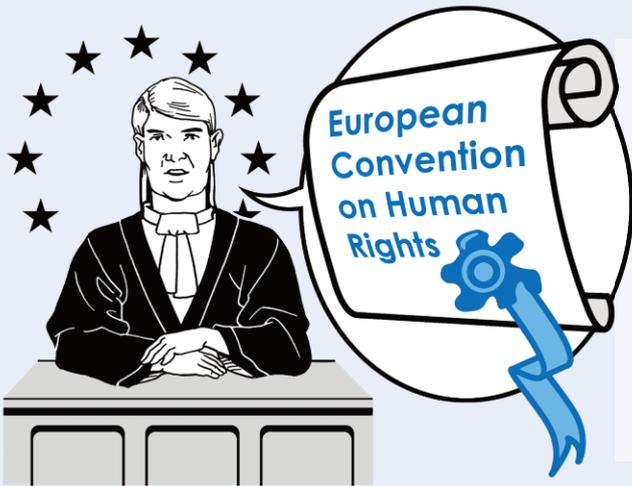
This is an agreement passed by the **Council of Europe**.



This is a group of countries, which came together after the Second World War to stop such terrible acts happening again.



It has its own Court of Human Rights in Strasbourg in France.

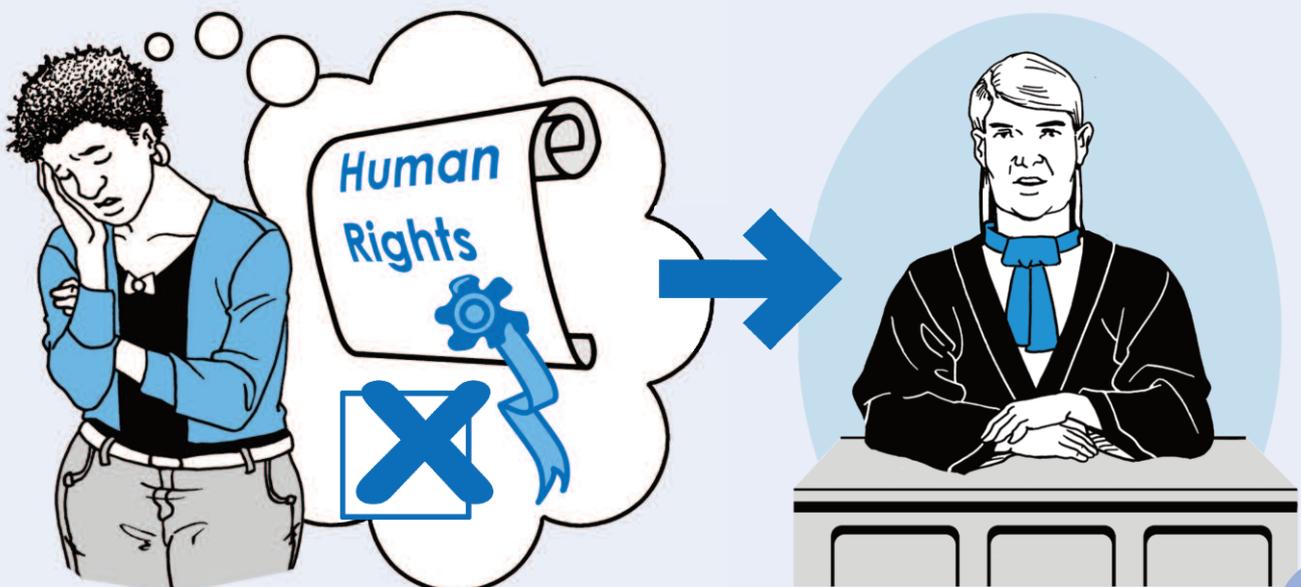


You can go to this court to claim your rights under the Convention. You can use the courts in this country, too.



In this country we have the **Human Rights Act** which brings all of the rights in the European Convention on Human Rights into UK law.

What this means is that if people are not respecting your rights, there is something you can do about it.



## What are your human rights?



It is against the law for a **public organisation** (like a government department, council or the police) to ignore your right...



...unless there is a law which means that it couldn't act differently. There are 16 rights in the **Human rights Act**.

## Right to life

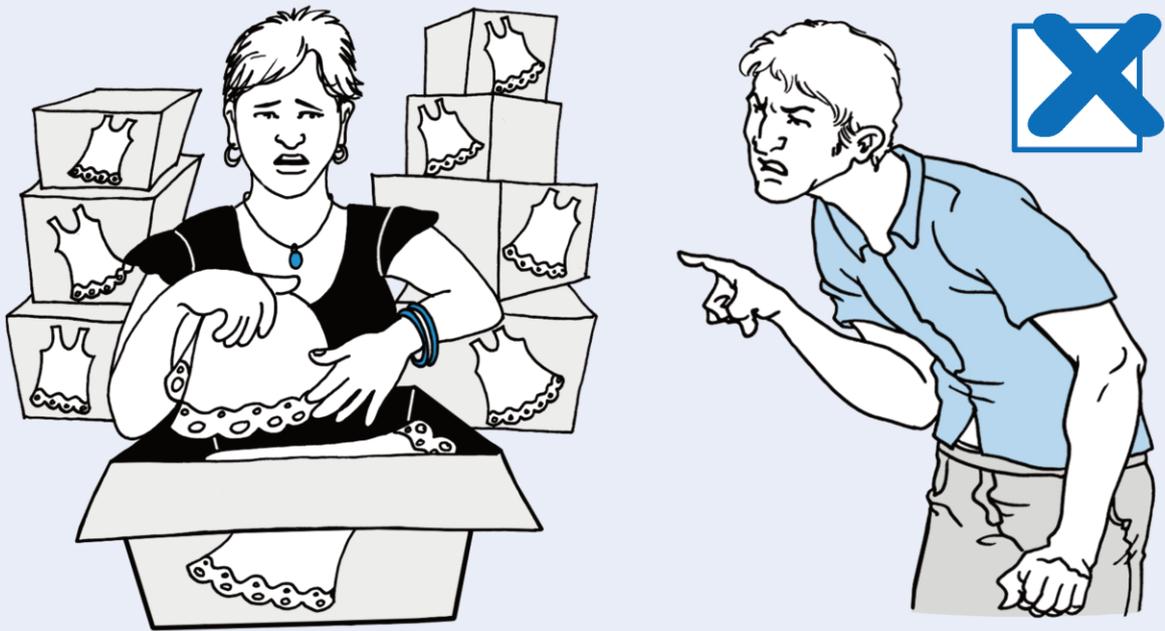
You have the right to have your life protected by law. There are very few times when the State can take away someone's life.



You have the right not to be tortured or hurt in cruel ways. Nobody should hit or hurt you - even if they say you have behaved badly.

## Stopping slavery and forced labour

You have the right not to be treated as a slave or forced to do certain kinds of work.



People can't make you work for free. You should get paid for the work you do.

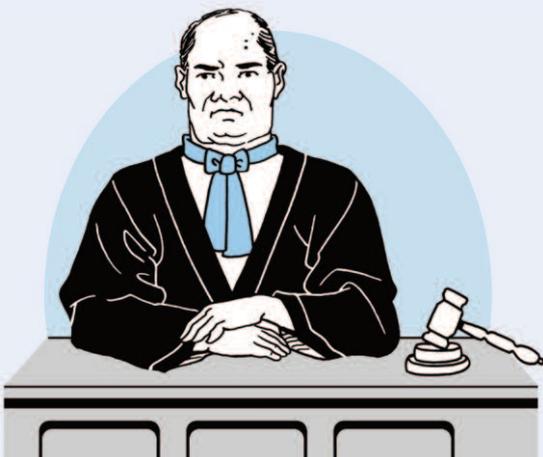


## Right to freedom and security



You have the right to freedom. You should not be arrested or locked up without a good reason.

For instance if the police have reason to think you have done something criminal.



If you are arrested, the police must bring you before a court.



Sometimes staff may stop you doing something you want to do. Sometimes they may make you do something you don't want to do. These are known as **restrictive practices**.



To find out if this applies to you, speak to your advocate or a member of staff.

## *Right to freedom and security*



Where your private rights are involved (like when someone says you owe them money), you have the right to have your side of an argument heard.



The trial must be independent and fair. It has to be in public. It has to be heard fairly and quickly.

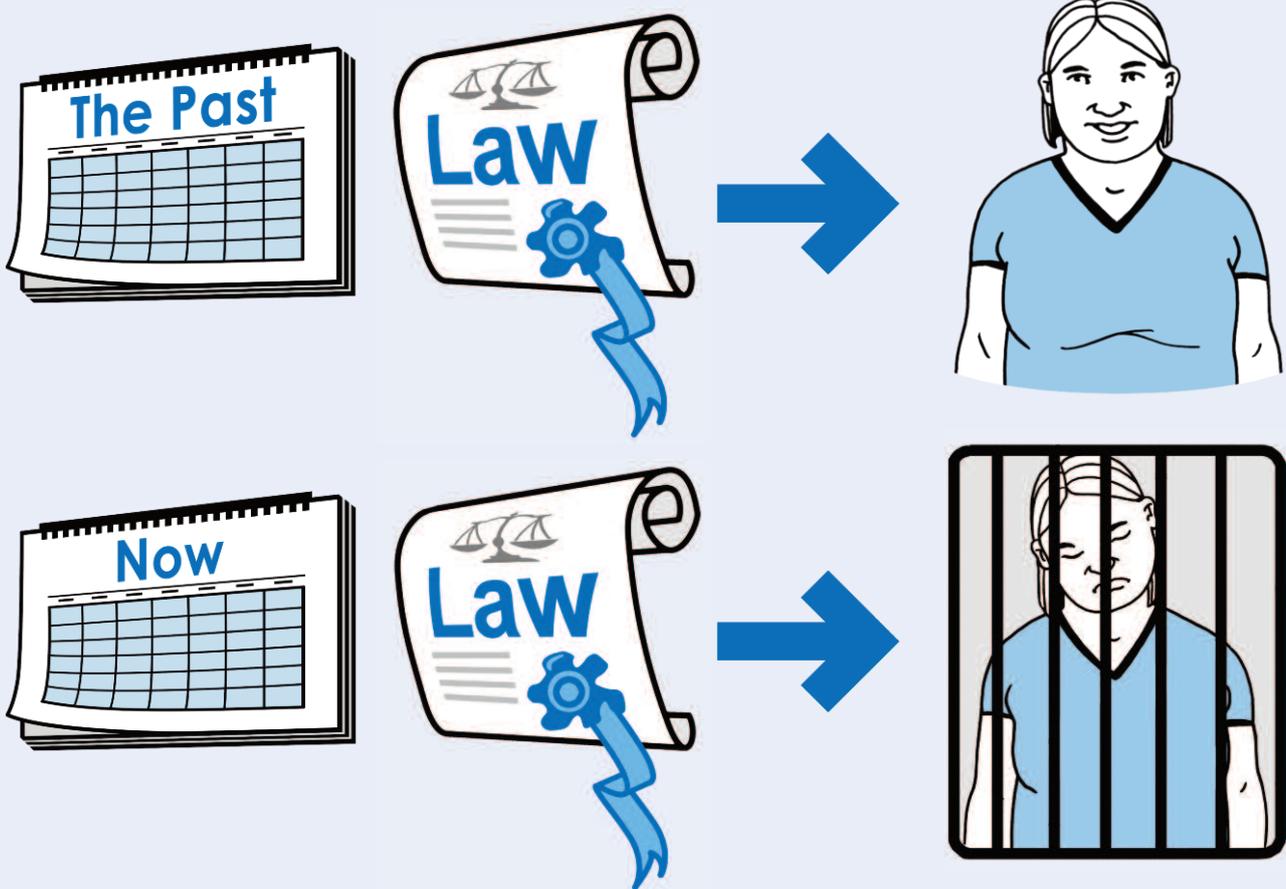


You are innocent until you are proved guilty. You have the right to defend yourself, to get legal help and to be told clearly about the case against you.

Nobody can say you are guilty of a crime unless a court says so.



## No punishment without law



Normally, you can't be found guilty of a crime for something you did which was not against the law when you did it.



You can't be made to stay longer in jail just because the punishment for your crime is made longer when you are in prison.

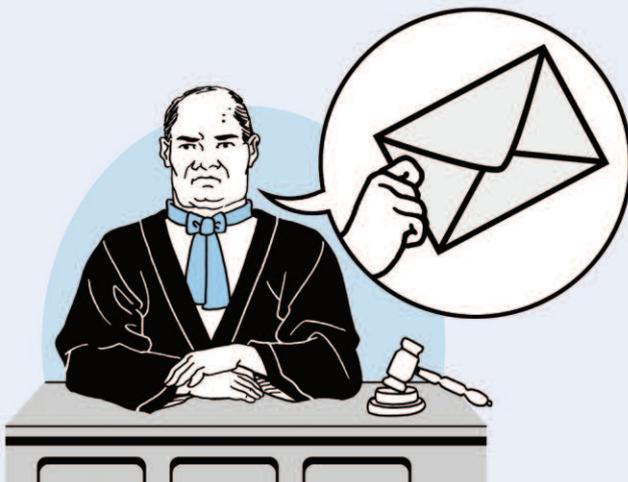
## Respect for private and family Life



You have the right to respect for your private and family life, your home, your letters and emails.



You should be safe at home and have time to yourself. Staff shouldn't read your letters or listen to phone calls...



...unless the law says they can and they need to for a good reason, for example, to stop a crime.

## Freedom of thought, religion and belief

**My beliefs**



You are free to believe what you like. Other people should not tell you what to believe. These beliefs may be part of your religion.

**My ideas**



You should be able to believe the ideas which you think are right.



And if you want to go to church, the temple or mosque, nobody can stop you. If you don't want to go, that's your right as well.

## Freedom of expression



You have the right to hold ideas and have your say - even if other people don't like your views.



You have the right to read books and newspapers, if you want to.

You should be able to say and read what you like – as long as you respect other people.



## Freedom of assembly and association



You have the right to get together with other people in a peaceful way. You have the right to join a union or group.

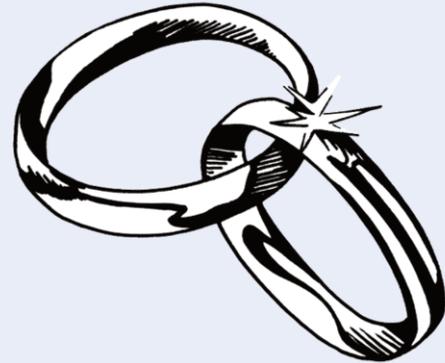


There could be times when this right may be restricted to stop crime or for the protection of the rights and freedoms of others.

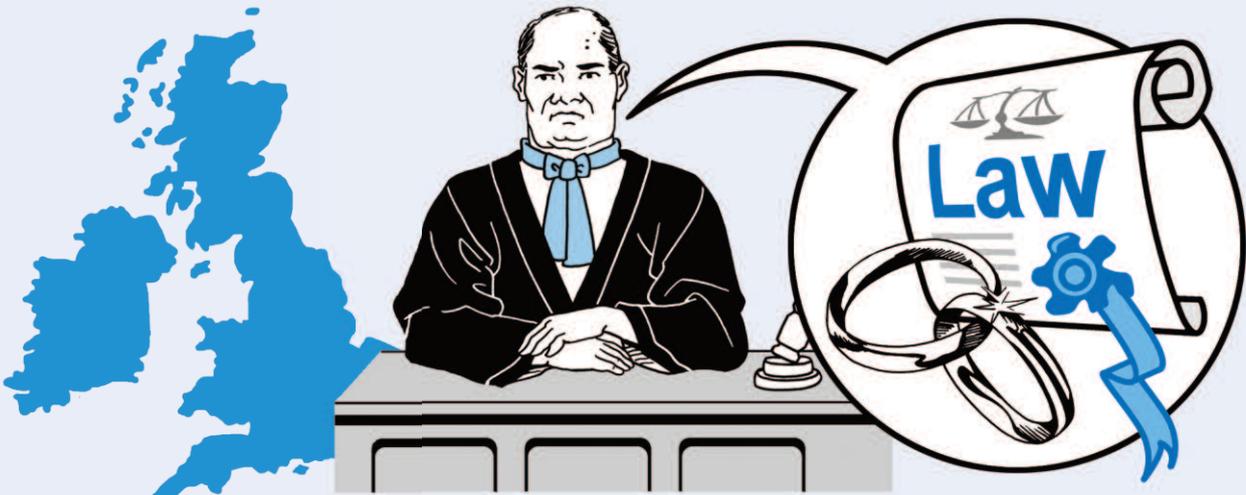


But this can only be done if it is really needed. The police cannot interfere with your rights more than is needed.

## Right to marry



You have the right to marry and start a family - even if your family or staff worry about you doing this.



The law in this country says how and at what age this can happen.



## Stopping discrimination

Everyone must have equal rights. You should not be treated unfairly because of your: **race, religion, sex, age, political views, disability, or anything else.**





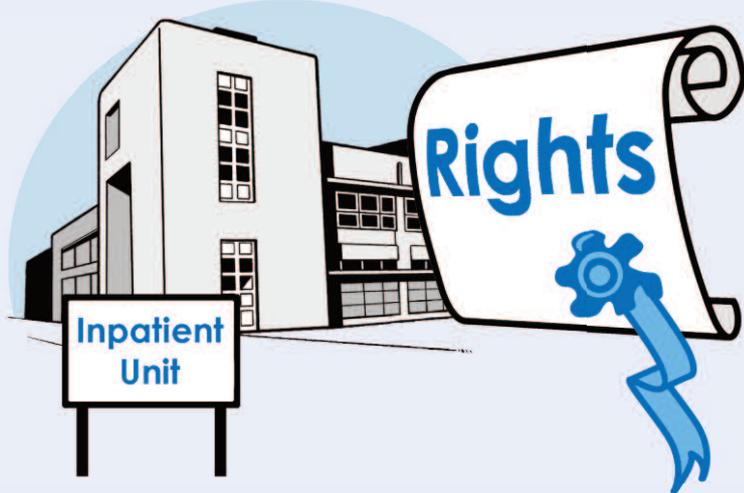
If you think your rights aren't being respected you have the right to advice from a solicitor.



Ask someone to help you find a solicitor close to you.

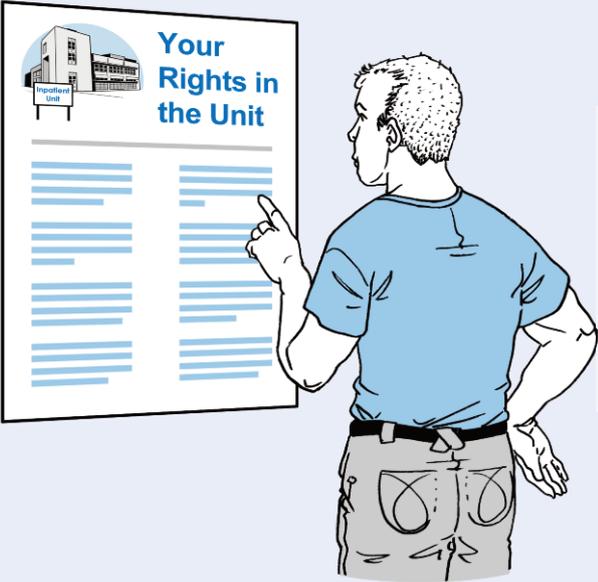


There are also a number of helplines who can give you advice, their details can be found on **page 196** of this pack.



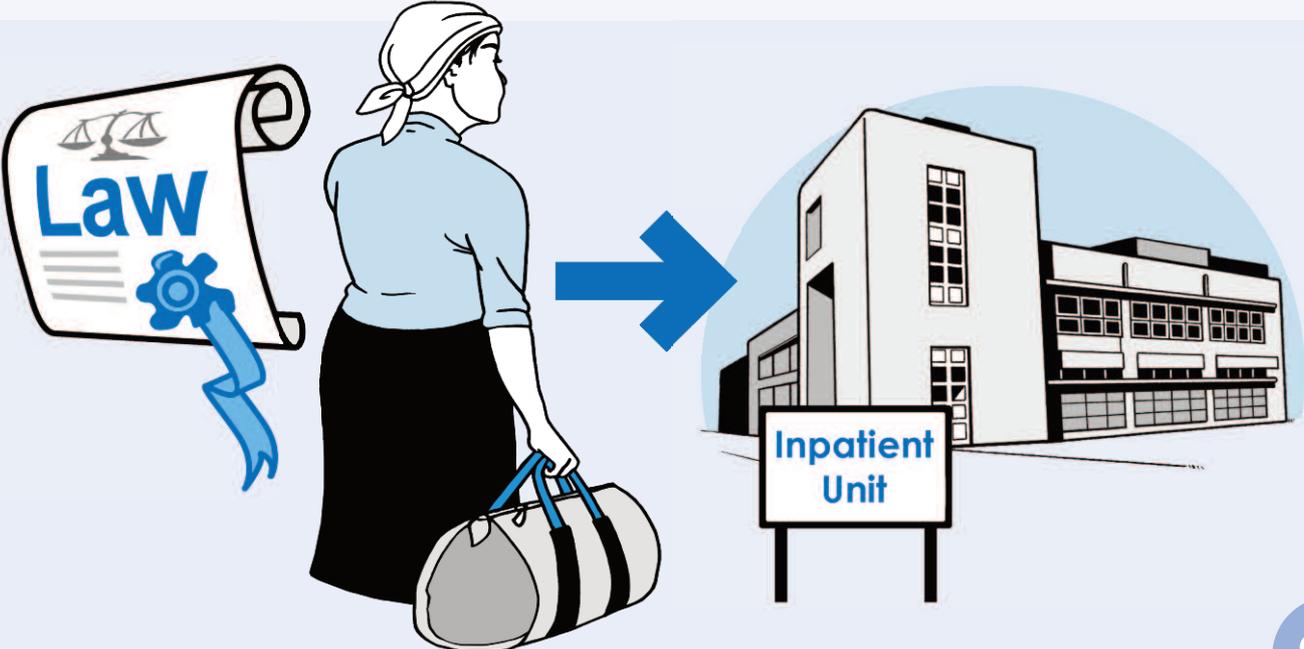
What are my rights?

*In the unit*

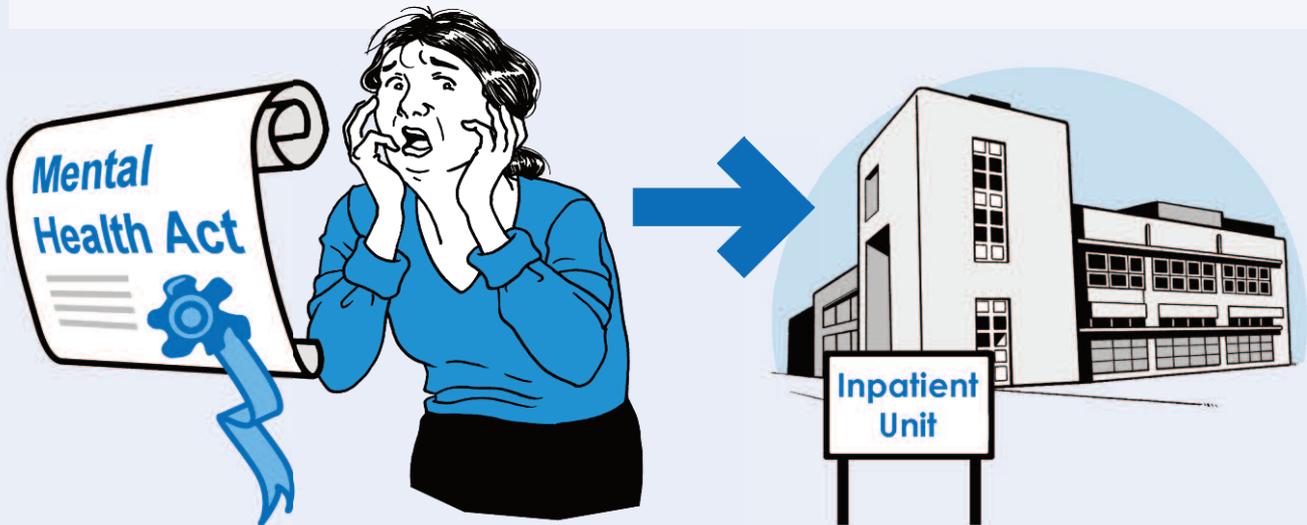


While you are in the unit you have a number of rights.

These may be slightly different depending on which law you came to the unit under.



You may have been admitted to the unit under the **Mental Health Act**. If you did you might hear people talk about **being sectioned**.



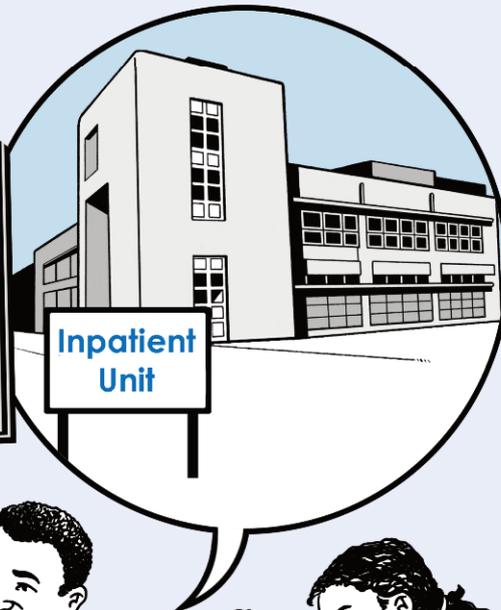
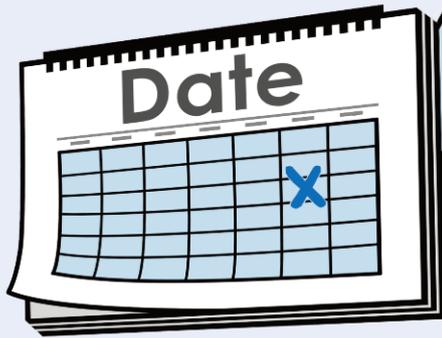
What they mean by this is that you are being held in the unit for assessment or treatment for a mental health condition.



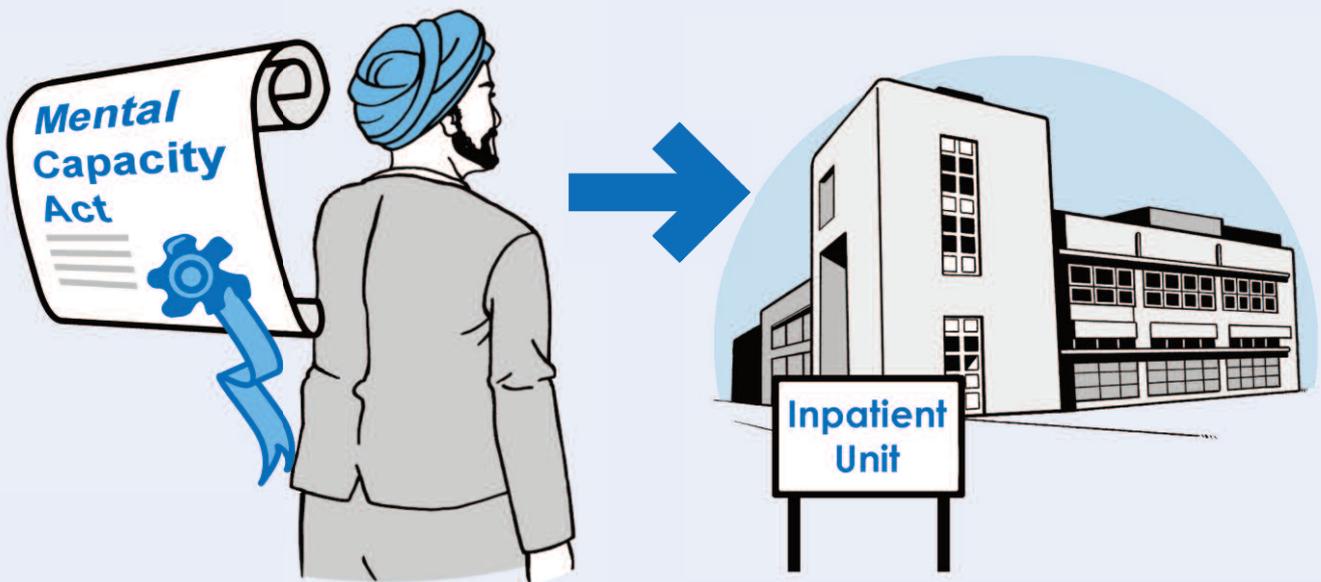
If you are in the unit under the Mental Health Act, you have the right to challenge being there if you do not think you should be.



You also have the right to a **Solicitor** to help you to do this. The staff at the unit should provide you with a list of local solicitors who can help you.



The time you have to spend in the unit should be reviewed regularly, and it is important that this happens.



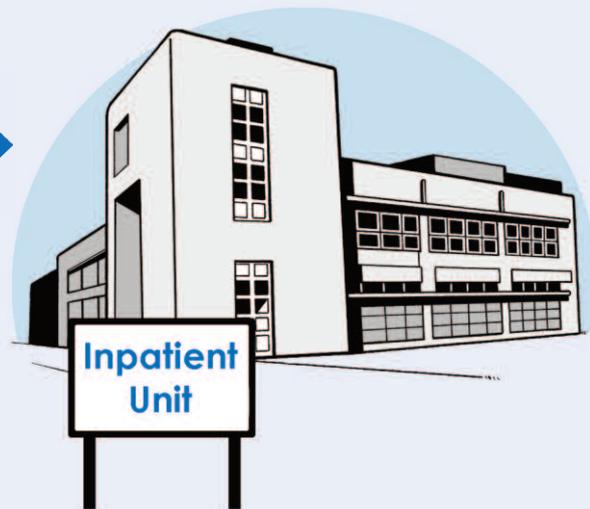
You may have been admitted to the unit under the Mental Capacity Act. This means that you need help from other people to make decisions about things, such as what treatment you should have or where you should live.



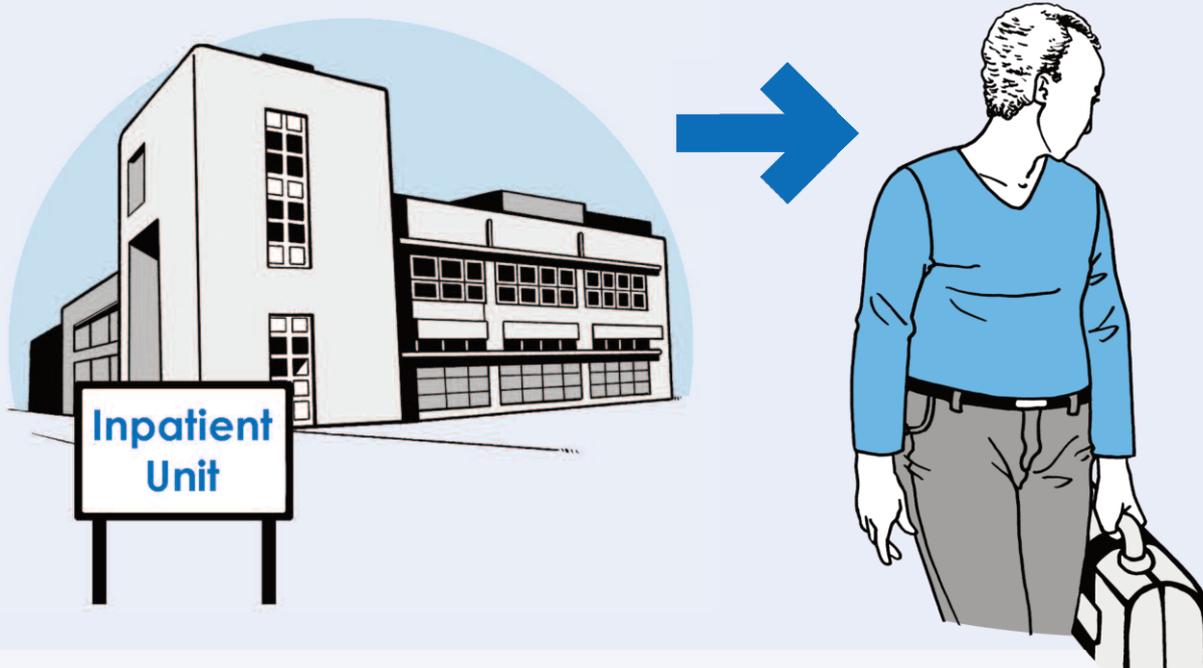
If you are in the unit under the Mental Capacity Act, you and your carers have other rights, and they can also help you to challenge being in the unit if you do not think you should be.



Even though you may find it difficult to make decisions on your own, the people involved in your care should include you in a way you understand when they make decisions about you e.g. with easy read information.



The third way of being in the unit is as an **informal patient**. This means that you have agreed by yourself to spend some time in the unit for assessment or treatment.



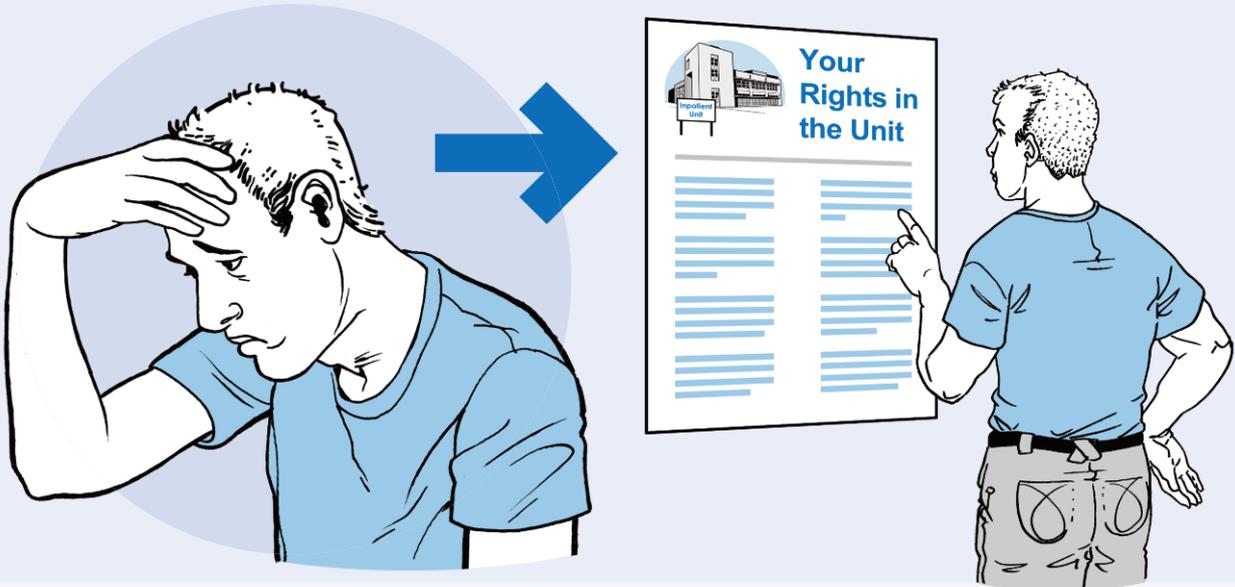
As an informal patient you also have rights, including leave outside of the unit, and to ask to leave if you no longer think you should be in the unit.



Whatever the reason you are in the unit, you have the right to an advocate to help you have your voice heard.



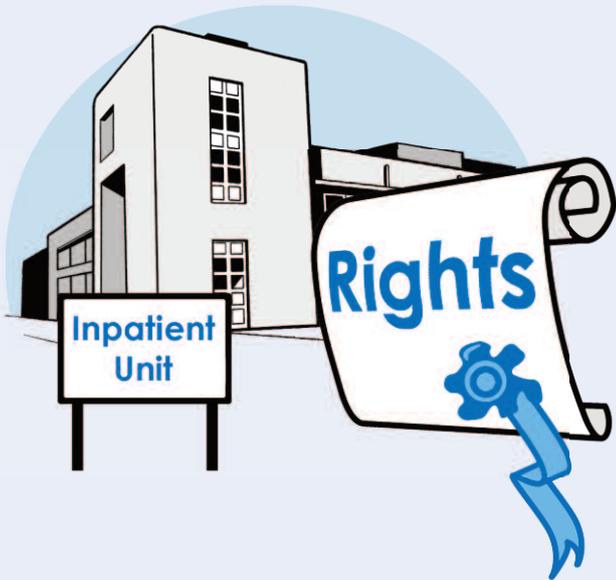
There is more information on advocates and the details of your local organisation on **page 63**.



This pack does not include all of your rights while you are in the unit, however it is very important that you know what your rights are and what to do if you are not happy.



You should ask a member of staff, or your advocate to explain what your rights are in a way that you understand and should have help to challenge your stay in the unit if you want to.



*Below is a form which should be signed by you and a member of staff or your advocate which says that you have been told what your rights are while you are in the unit.*

*I .....*

*have been told what my rights are while I am in the inpatient unit and what to do if I am not happy and I understand the information that has been given to me:*

**Signed:** .....  
*(Patient)*

**Signed:** .....  
*(Staff member/Advocate)*

**Witnessed by:** .....

**Date:** .....



What  
are my  
rights?

## When I leave the unit

*I don't think I am getting the right support, what can I do?*



If you think you need support in any way, you should get someone to help you ring your local authority, or social worker and ask for a **needs assessment**.

You can email, send a letter or drop in to your **local authority** to ask for an assessment.

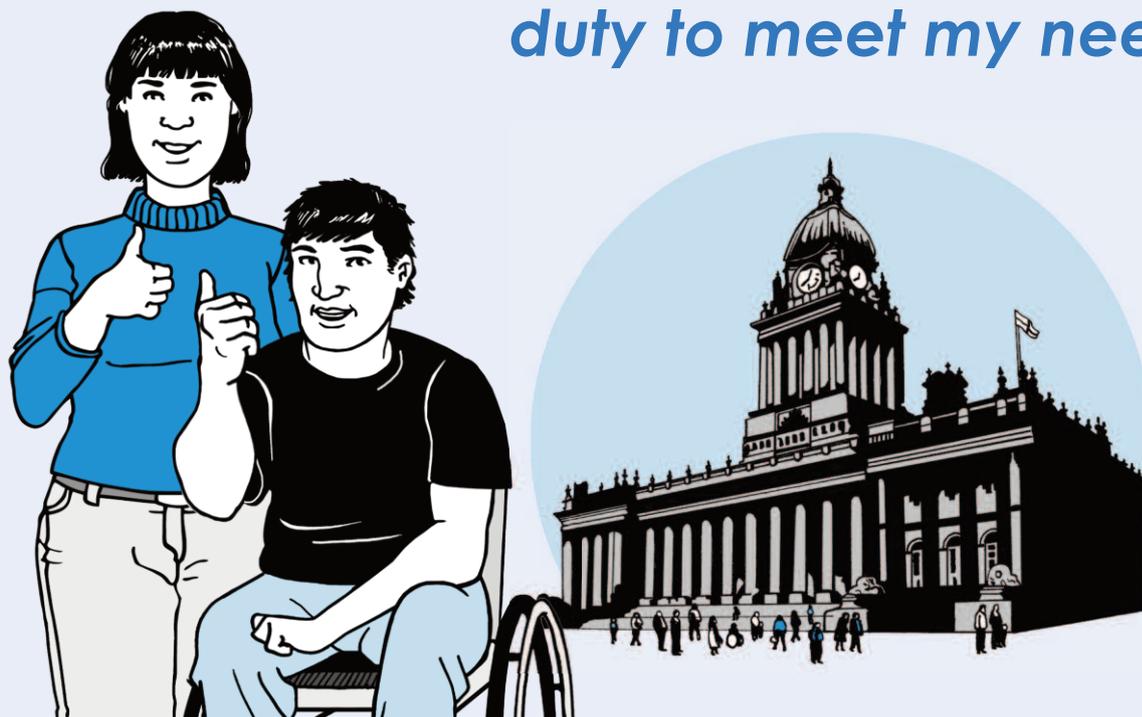


You can add their details to the local services directory of this pack on **page 139**.



If you need urgent support you should let social services know this as they are able to provide emergency support to you before you have had an assessment.

## Does the local authority have a duty to meet my needs?



The **local authority** has a duty to meet all of your eligible social care needs .



**Eligible** means that you have to have certain needs to be allowed support. Your local authority will be able to give you a list of these.



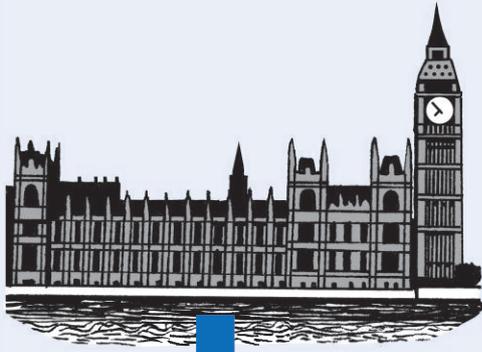
If you also have a long-term health condition, the local authority must work with the NHS to make sure you get the services you need.



If you have certain needs, the local authority must say how they are going to meet them in your care plan. More details about your care plan are on **page 41** of this pack.



Your care plan should be reviewed at least once a year to make sure that your needs haven't changed.



## Benefits

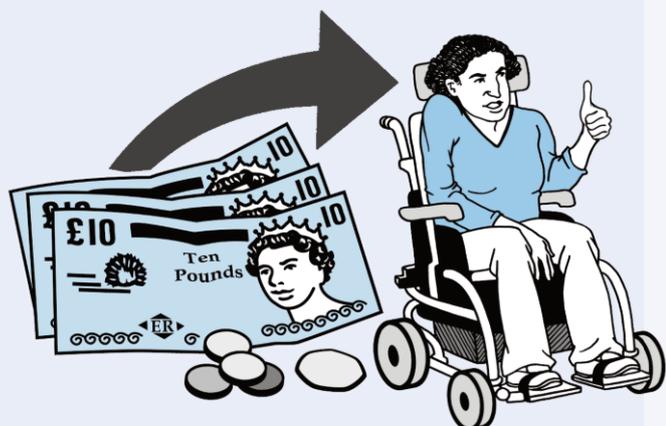
### What is benefits money?

**Benefits money** is money you can get to help pay for things you need. The money comes from the government.

The part of the government that decides what benefits money you can get are called the **Department for Work and Pensions**.

They are called the DWP for short. Benefits money can be hard to understand. Ask someone you know for help if you need it.

# Personal Independence Payment



**Personal Independence Payment** is a new type of benefits money. It is called PIP for short. It is for people with a disability or serious health problem.



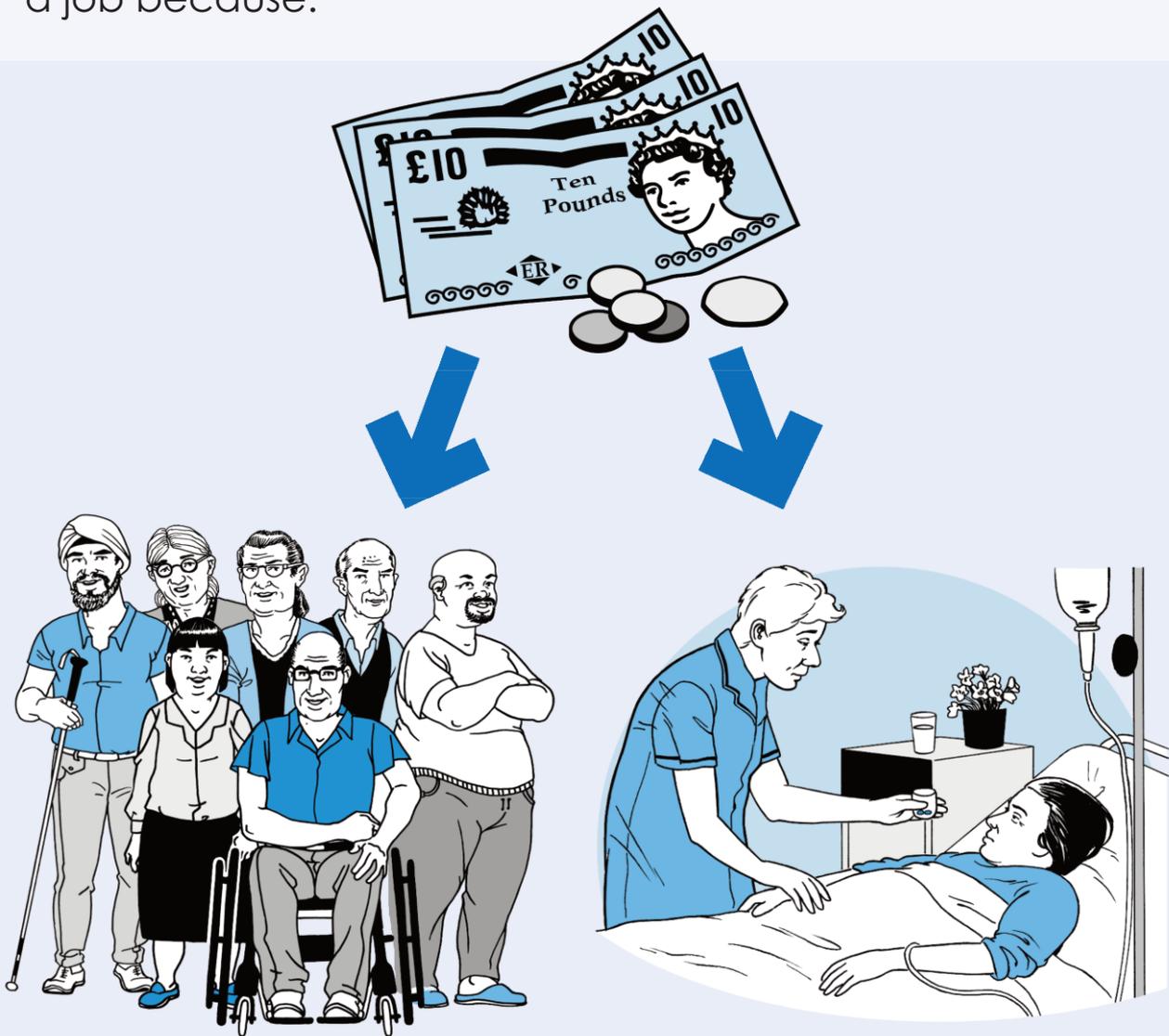
Personal Independence Payment is for people aged 16 to 64. It is instead of another benefit called Disability Living Allowance or DLA for short.



Personal Independence Payment is to help disabled people with the extra things they need because of their disability.

# Employment and Support Allowance

This is often shortened to ESA. **Employment and support allowance** is a benefit for people who find it harder to get a job because:



- They have a disability

- They have a problem with their health and will have this problem for a long time or the rest of their lives.



If you have questions about your benefits or whether getting a job might affect your benefits you can speak to JobCentre Plus.

You can either call them on **0845 604 3719**

Or visit your local JobCentre to speak to an advisor.



My nearest  
JobCentre  
Plus is:

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# Employment and Support Allowance



You can apply for the benefit by calling the Jobcentre Plus Claim line.  
Telephone: **0800 055 6688**  
Textphone: **0800 023 4888**



You can ask someone to help you with this call. The person on the telephone asks questions about your disability or health problems.



After the telephone call the person you talked to sends you a letter. The letter should list the things you have told them.



Check the letter to make sure what is written about you is true.



If you do not want to claim over the telephone you can get a claim form instead. To ask for an **ESA1 claim form**

Telephone: **0800 055 6688**



Or go to your local Jobcentre Plus office or you can fill out the form on the website:

**[www.dwp.gov.uk/service](http://www.dwp.gov.uk/service)**



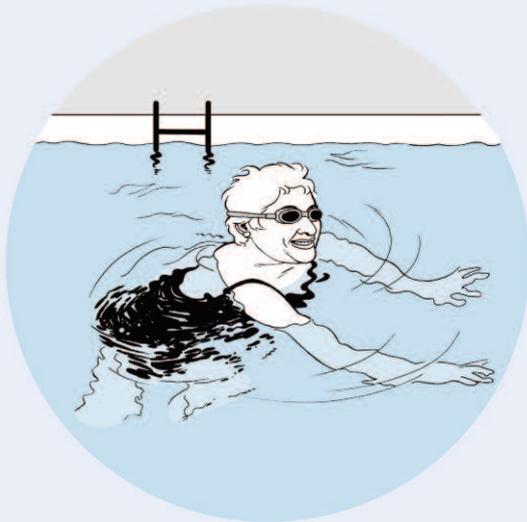
Fill the form in and send it back to Jobcentre Plus.



## *I am going to have a personal budget, what does this mean?*

A **personal budget** is money which is given to you by the local authority.

*This money can be used by you in two different ways:*



1

By services being provided directly from your local authority. For example, they might pay for you to go to community activities.



2

They might give you a **direct payment**.



**Direct payments** are cash payments given directly to you (or your family or carer if you cannot decide how to spend the money yourself) so that you can choose what services to buy and organise your own support.



Direct payments mean that you have more choice and control over the care that you get, for example you can choose and employ your own carers.



If you need more help in managing your direct payments you can ask for support from your local authority.

# Will the NHS pay for any of my care?

The NHS and local authority must work together to make sure you have all the care and support you need



Sometimes people who have complex needs may be entitled to **NHS Continuing Health Care**.



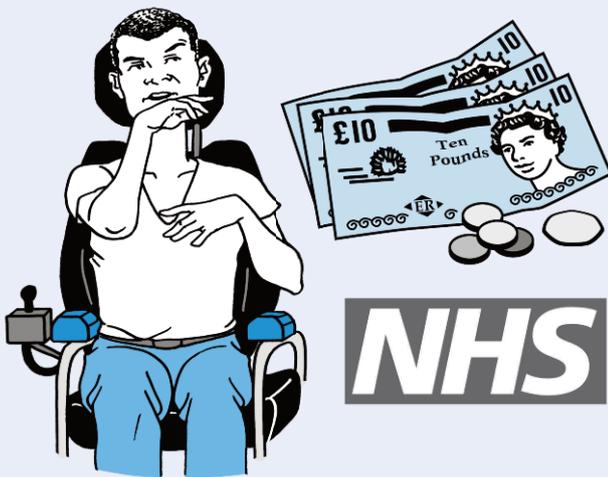
The NHS will pay for this care if you are assessed as having a **primary health care need**. This means you can have the skilled care that you require.



To get support you must have a **continuing health care assessment** which will be carried out by a nurse who will look at all of your different needs.



If you think you should be entitled to NHS Funded care, you should speak to staff at the unit or your social worker or advocate and ask for an assessment.



The NHS can be responsible for paying for your health and social care.



If someone is detained under certain sections of the mental health act – then after discharge they are entitled to have their mental health care needs met under section 117 of the mental health act. This is separate from **NHS Continuing Health Care**.

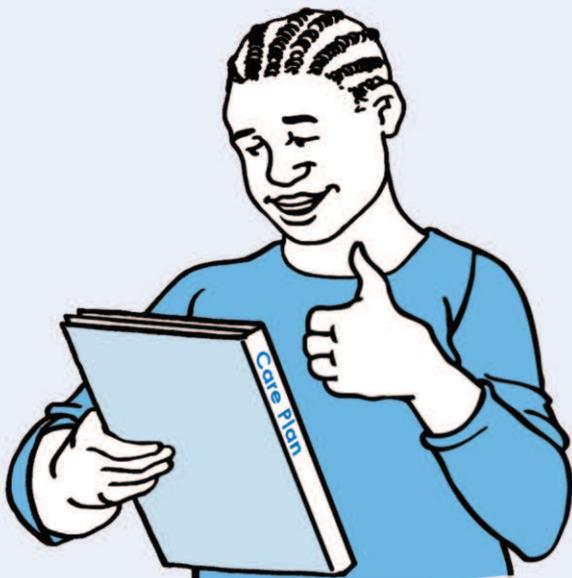
## *I am not happy with my care plan, how do I challenge it?*



Details about what your care plan should look like are on **page 37** of this pack.



The local authority should give you a draft of your care plan before it is finalised.



This means that you can have a look at it and make sure you are happy with it.



Once you sign your care plan it means you have agreed to it, so it is very important that you look at it carefully.



Sometimes you might feel under pressure to accept a care plan you are not happy with.



If you are not happy with your care plan you should tell your social worker and explain why. You can request a care and treatment review to challenge the care plan.



If this doesn't work you should think about making a formal complaint.

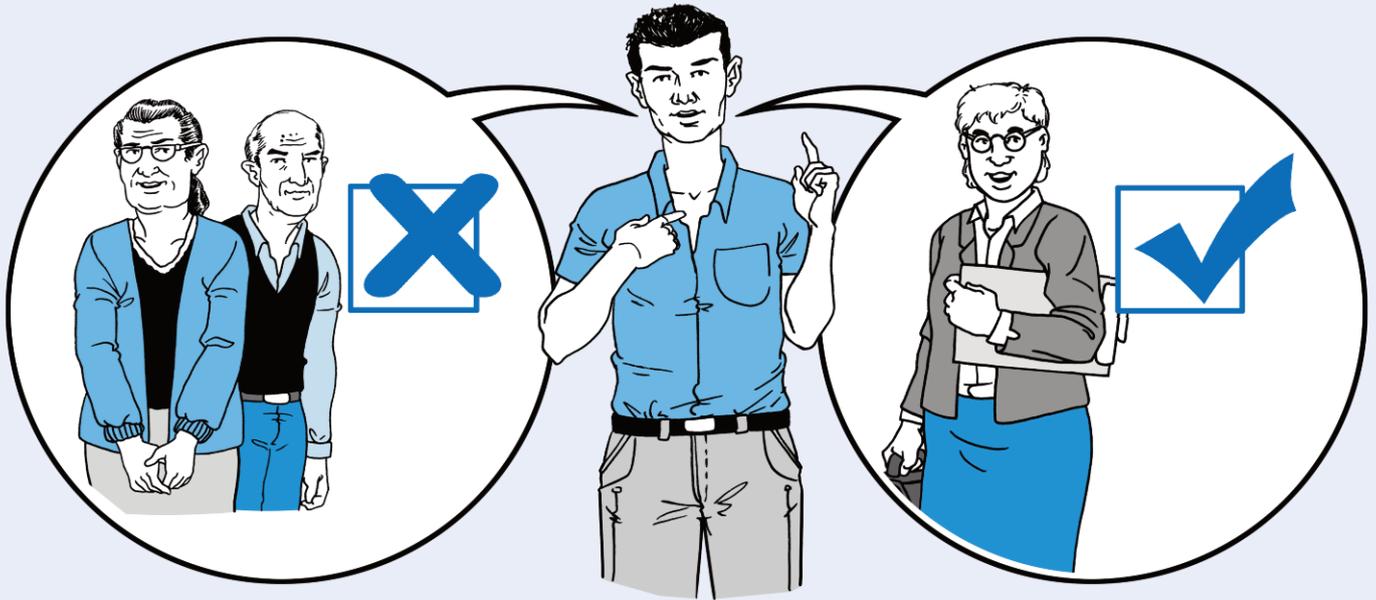
## *Do my family and carers have to be involved in the decisions that are made about me?*



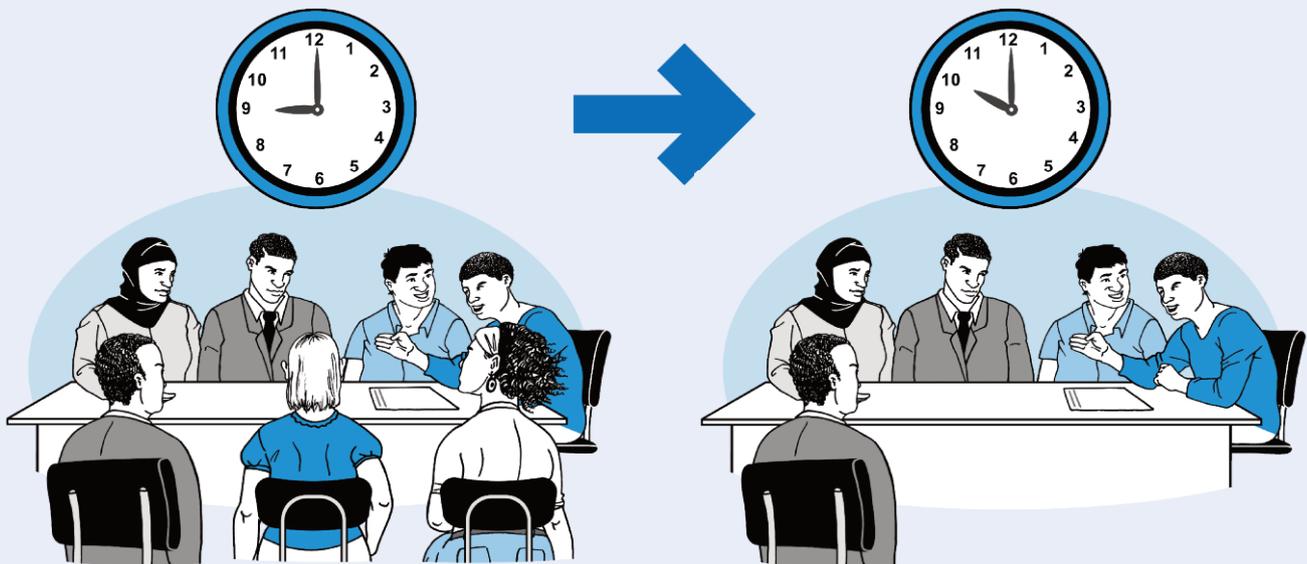
If you can make your own decisions your family and carers do not have to be involved in what happens with your care and support.



Sometimes people might not feel comfortable saying certain things in front of their family or carers, this is fine.



It is your decision who you have at your meetings and who is involved in your care. You should not feel pressured to have certain people involved in your care if you do not want them to be.



You may want your family to come to part of a meeting, and ask them to leave while you speak to professionals about private things.

If you need support but want someone independent you can have an advocate to support you. An advocate will help you to get your voice heard.



More details about your local advocacy service and how they can help you start on **page 70** of this pack.



## How can I get extra support at home?



If you are not getting the right support at home you should contact the local authority and ask them to carry out another assessment.



Their details are in the contacts directory of this pack.

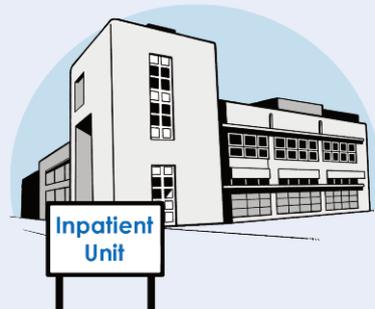
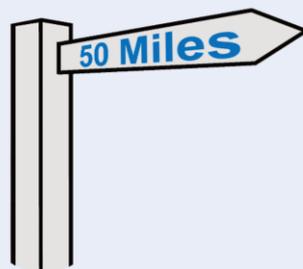
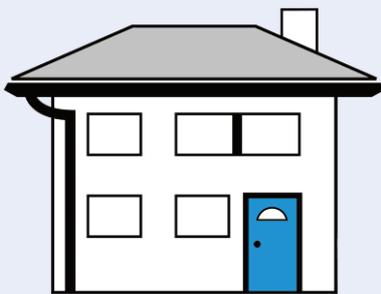


*They want to send me to a placement too far from home. How can I challenge this?*



The local authority and NHS must make sure that they meet your needs.

Sometimes the only suitable place they can find is far away from home. This is very difficult if you want to be near your family and friends.



It might be possible to challenge the local authorities or NHS decision to do this if it is not the best place for you.

It may also be argued that living far away from home is against your human rights under a law called the Human Rights Act 1998. This law says that you have the right to a private and family life.



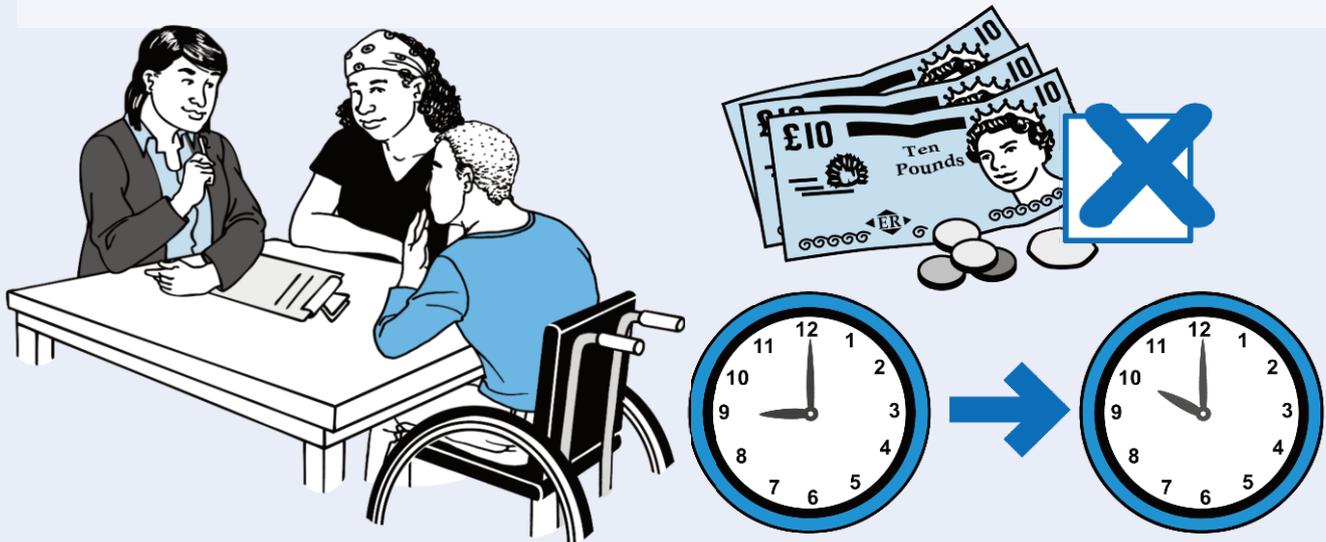
If you want to challenge a decision by a local authority you should get advice from a legal expert.



To complain about the NHS you can use your care navigator or local PALS service.

Ask your carer or advocate to help you ring a local Solicitor for legal advice.

Anyone can have legal advice for up to one hour for free and you may be able to get all of your legal advice and representation for free.



Solicitors can help you with lots of things, including problems with your care services, human rights issues, abuse and discrimination.

To find local solicitors who can help you, contact the law society.



website: [solicitors.lawsociety.org.uk/](http://solicitors.lawsociety.org.uk/)  
telephone: **(0)20 7320 5650**  
(Monday to Friday 09:00 to 17:30  
charged at local call rates)



**What services can I use in the community?**



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What services can I use in the community?  
- contents



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Services



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Help and Support



131

Local Activities



133

Getting a job



# Services

*Use this section to write down, or draw the things you would like to do when you leave the unit.*

*When I leave the unit I would like to:*

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On the following pages is a list of **services in your local area**. You should ask your advocate, carer or a member of staff at the unit to help fill this out with you so you know who to contact.

# Local Service Directory



# Help and Support



My local doctor:

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My dentist:

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My local advocacy service:

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## My Social Worker:

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## Healthwatch: (see page 193)

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## NHS Complaints Advocacy Service:

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My local housing service:

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My housing support worker is:

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My local benefits advice service:

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## My local safeguarding team:

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## My local authority:

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## Any other support services:

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# Local Activities

Ask your advocate, carer or a member of staff to help you to fill out local activities and groups in your area that you would like to go to when you leave the unit.



My local swimming pool is...

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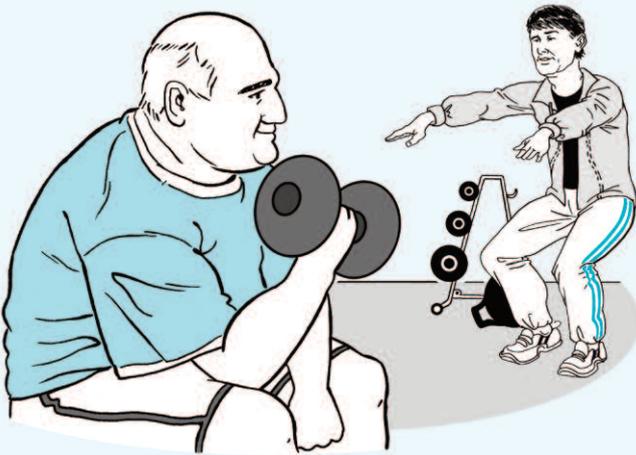
My local shops are...

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My local library is...

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My local gym is...

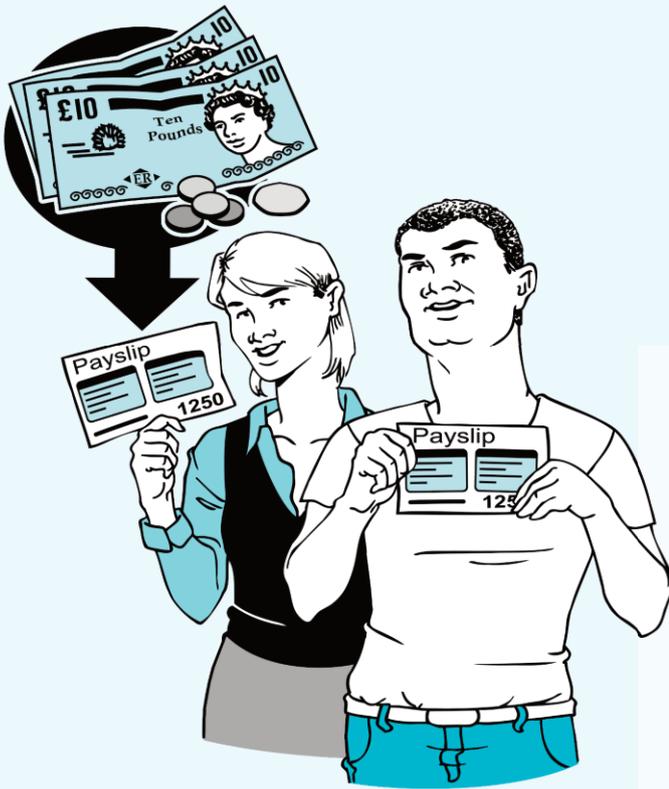
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Community groups I am interested in:

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## Getting a job



Getting a job makes you feel better about yourself. It also gives you more independence and gives you money which you can spend how you want to.



It is important that you have a job that interests you and helps you to build up your skills and confidence.



It might not always be possible to get the job of your dreams, but you should have a job that you enjoy.



The people you work with should respect you and support you.



The place you work should be accessible and have accessible information to help you do your job properly.



There are lots of ways of finding a job and getting support to apply for one.



You could contact your local job centre:

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Your local Citizens Advice Bureau:

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Your local college :

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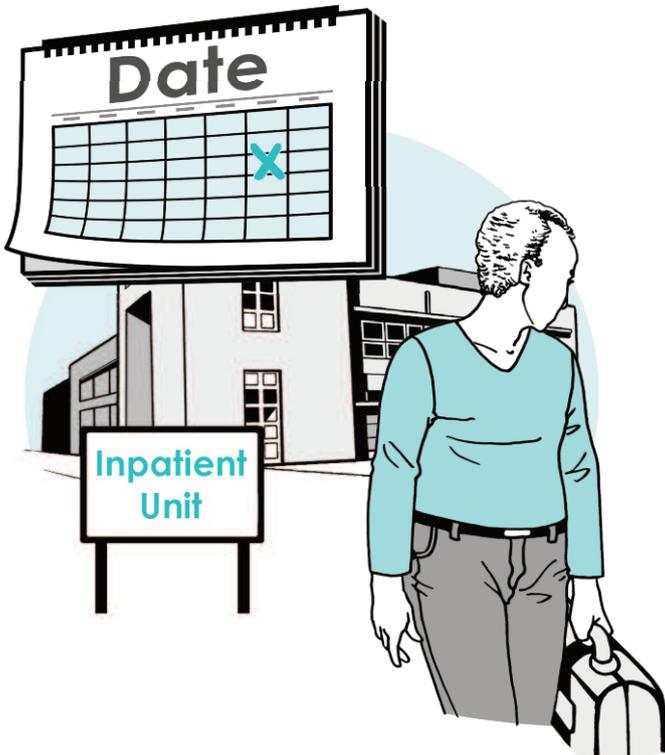


**What if things  
don't go to plan?**



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What if things don't go to plan?  
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My discharge date has been delayed



146

I am not moving to the place I want to





What if things don't go to plan?



Sometimes things will not go to plan, your discharge date might be moved, or you might not get to move to where you had planned.



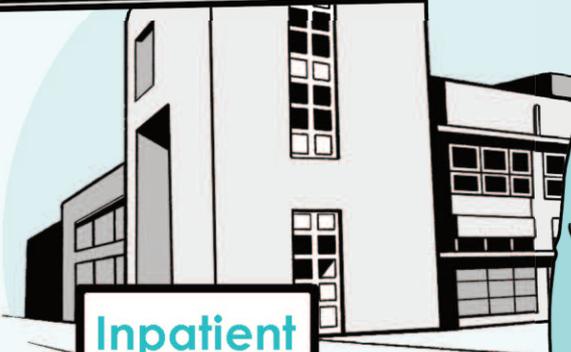
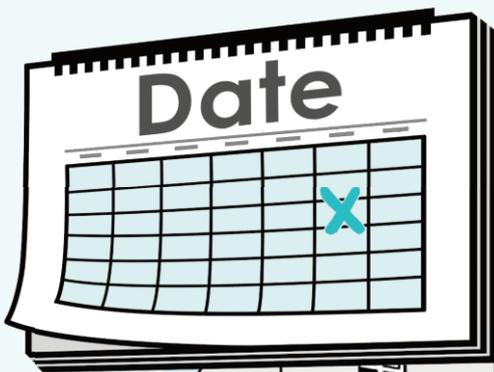
If you are not happy, it is very important that you let someone know, this could be staff at the unit, your advocate or family.



By letting people know you are unhappy, things can be done differently.

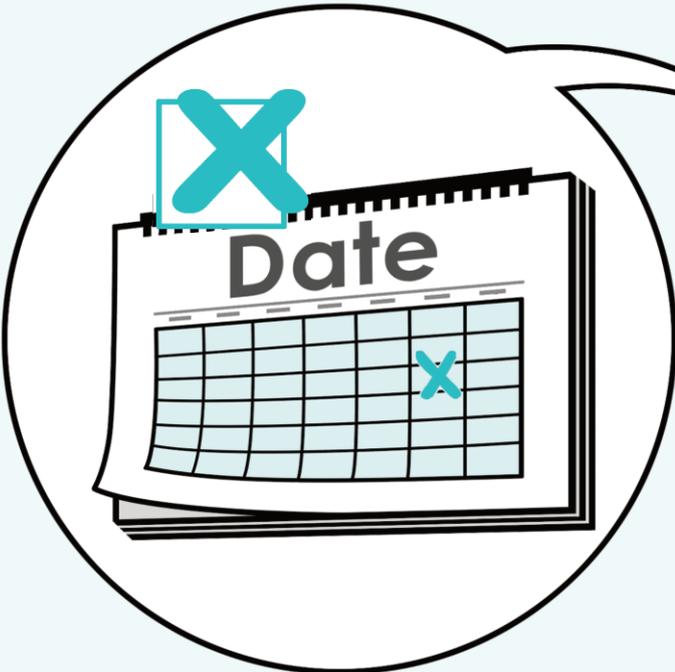


You should be involved in your care every step of the way.

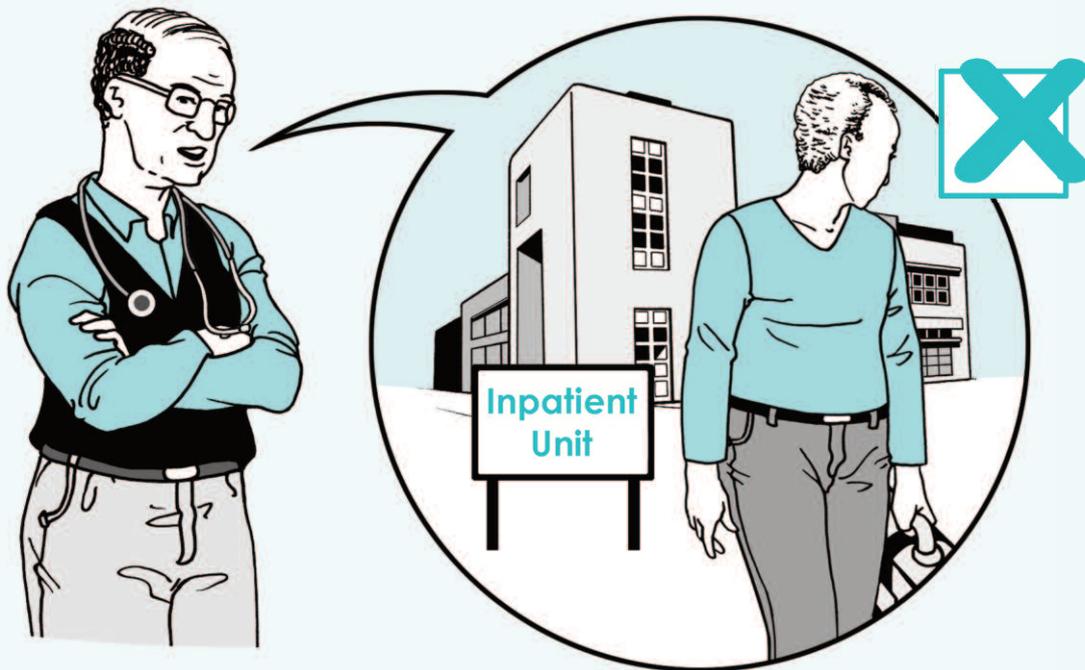


My discharge date has been delayed

*How can I challenge this?*



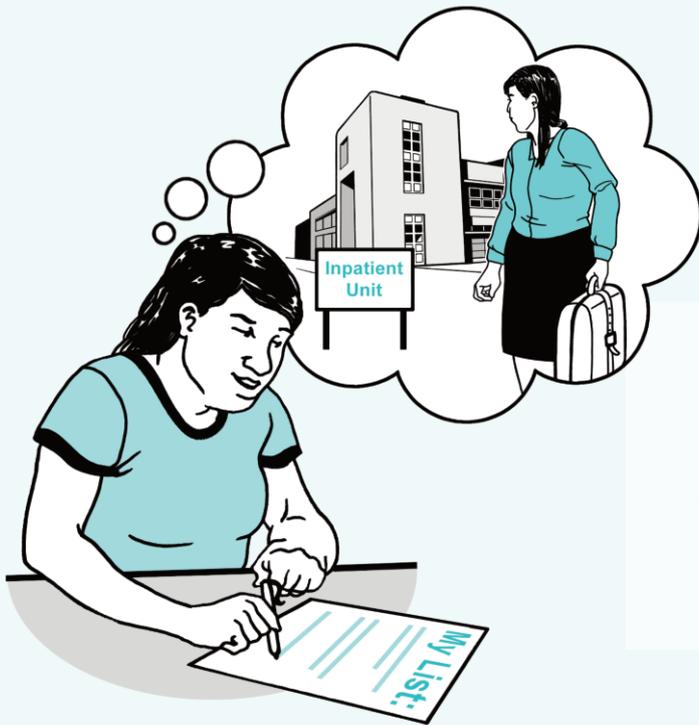
## *The Doctor said I am not ready to leave the unit, but I disagree.*



Your discharge date can be moved for different reasons. This might be because the Doctors feel that you are not yet ready to leave the unit.

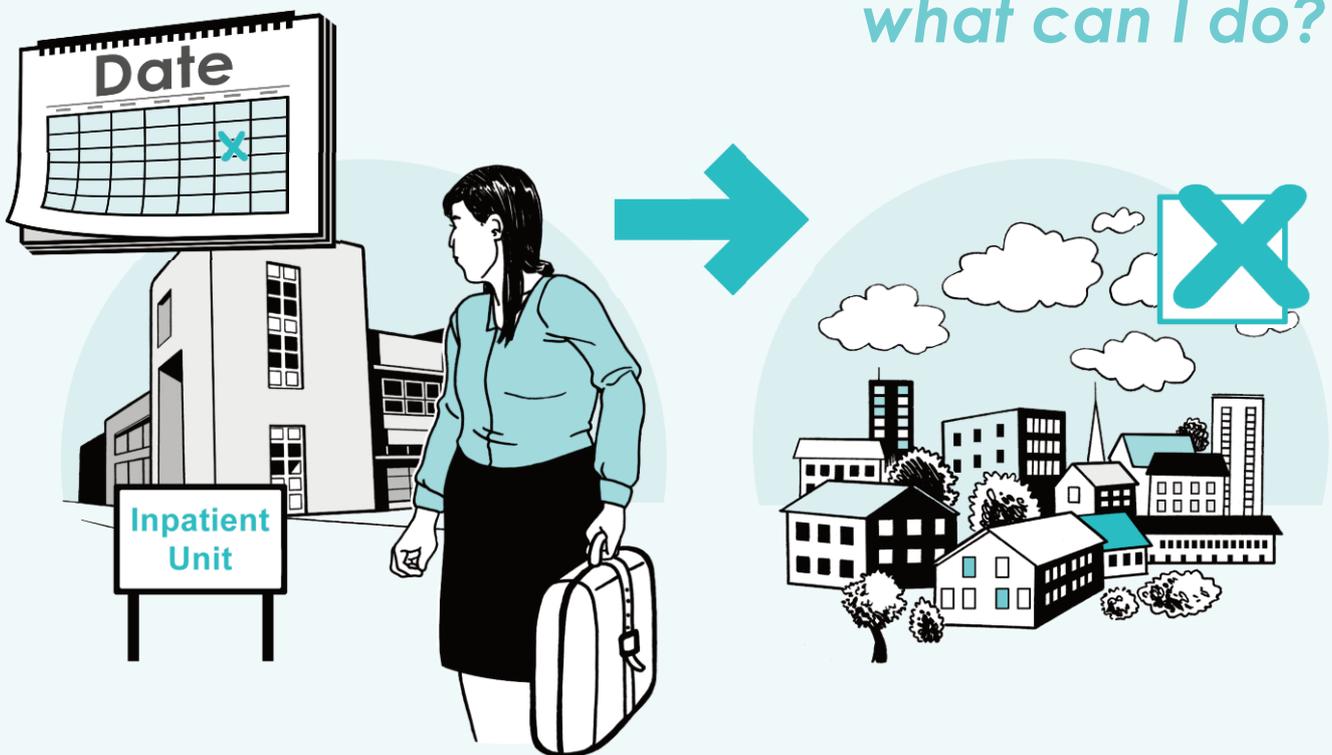


If you disagree and do think you are ready to leave the unit, you should speak to your Doctor straight away and explain why you think you are ready to leave. Ask your advocate, family member or carer to help you to do this.



It might help you to write down the reasons why you think you are ready to leave the unit.

*My discharge is delayed because community services are not available, what can I do?*



My discharge date may also be delayed because the services in the community are not ready yet.



If the NHS is commissioning the placement, before you are discharged the NHS must tell Social Services that you may need some support in the community .



Once they have been told, Social Services must come and give you a **needs assessment**.

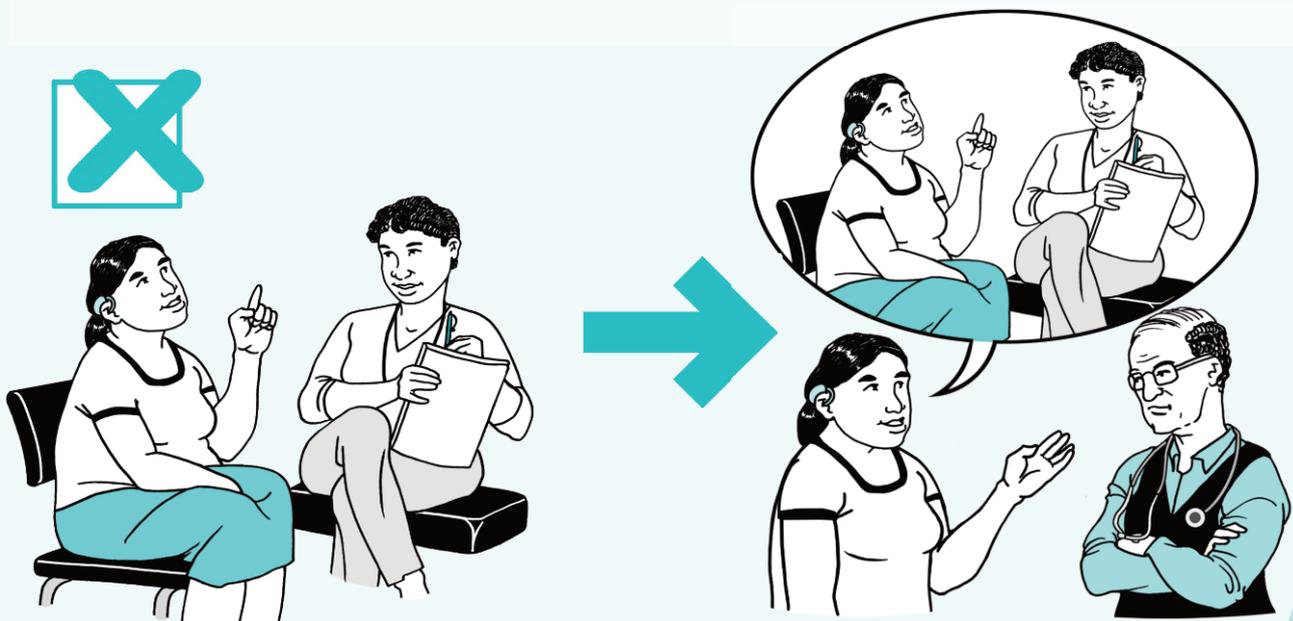
This assessment will help them to decide what support you will need.





After your assessment the unit must tell Social Services what day you will leave hospital, to make sure that your discharge is not delayed.

If you have not had a Community Care Assessment yet, or you think it wasn't done in reasonable time you should raise this with your Doctor at the unit and your local social services. Ask someone to help you do this if you do not want to do it by yourself.

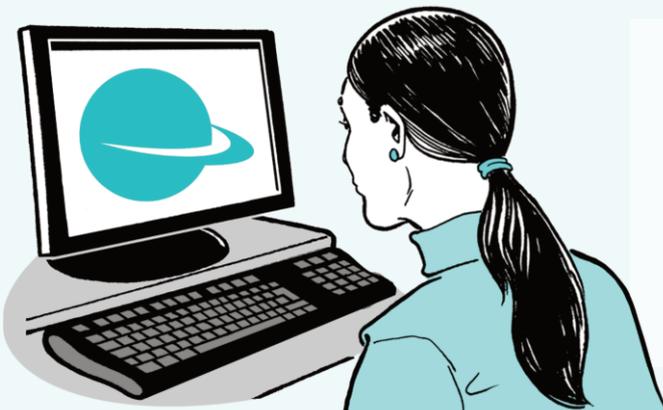




You could also consider making a formal complaint or contacting a community care solicitor for advice about what steps to take next.



There are more details on making a complaint in the next section, [page 164](#).



Your advocate can help you to find a solicitor or you can have a look on the internet:

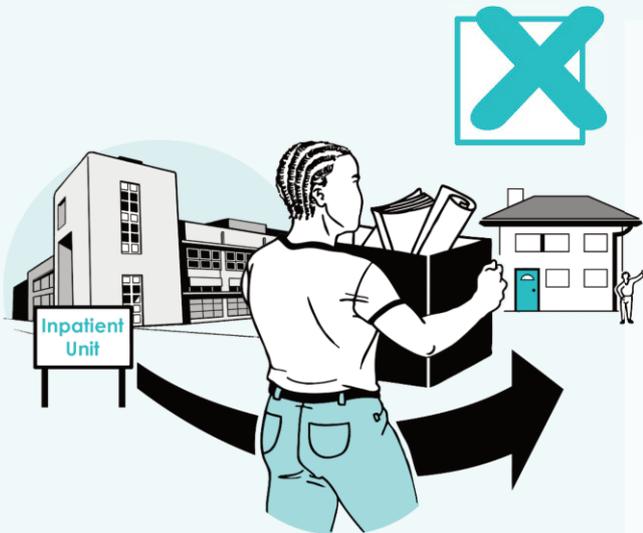
[solicitors.lawsociety.org.uk](https://solicitors.lawsociety.org.uk)

+44 (0)20 7320 5650



I am not moving to the place I want to

### What can I do?



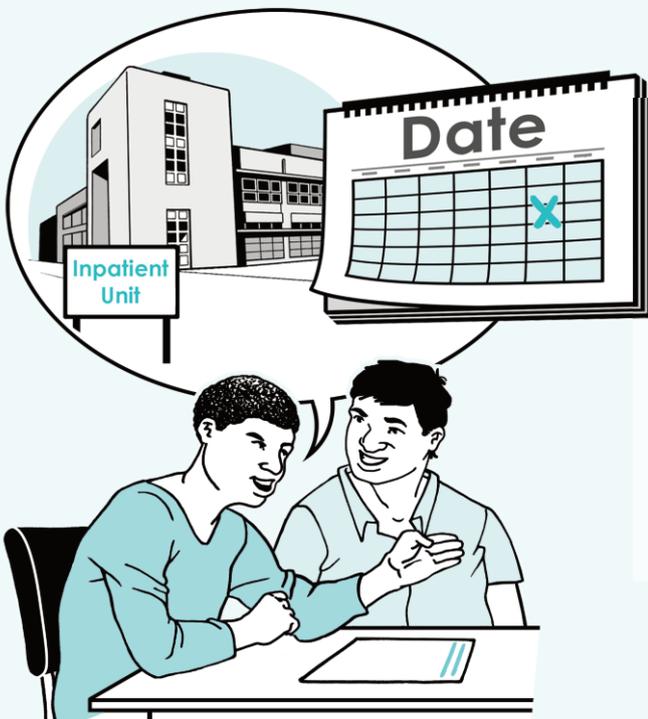
Sometimes you may be unable to move back to where you lived before because your support needs are different, and you might need extra help or support in the community.



The plans for when you leave the unit should be made as soon as you are admitted to the unit.



You should be involved in planning your discharge from the very start.



Your family, carer or advocate can also be involved in planning for when you leave the unit, but only if you want them to.

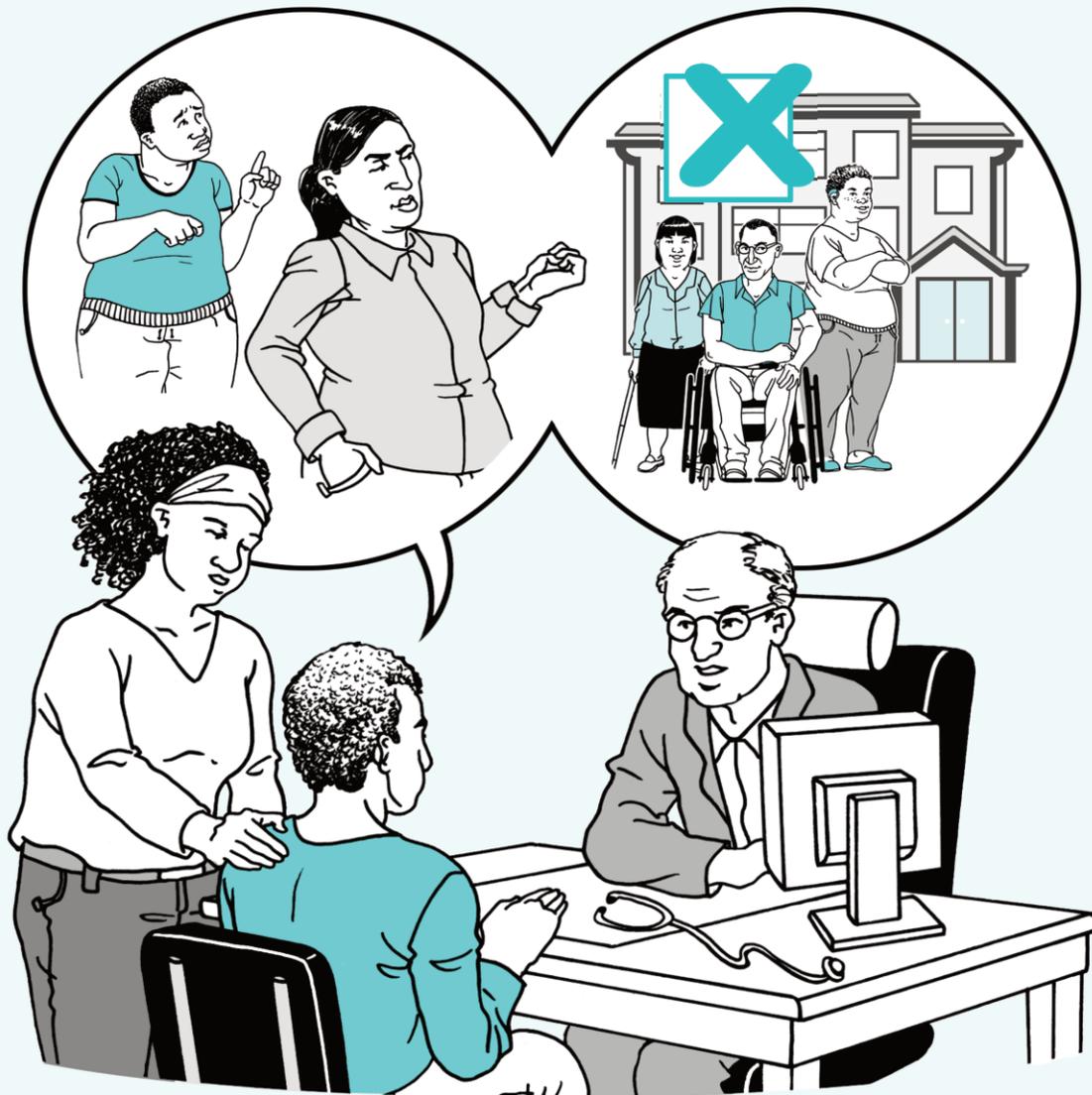


When decisions are made about where you should live, your views should be listened to.

If the people involved in your care do not think that where you want to live is best for you, they should explain why and tell you what support you will get to live the life that you choose.



This support should be right for you and should help you have as much independence as possible, so you should be involved in deciding on the right support for you.



If you are worried that you are not being listened to or that your new home is not right for you, you should raise this with your Doctor straight away.



Get help from your family or advocate to raise your concerns.

## *The local authority or NHS want me to go back to the inpatient unit. How can I challenge this?*

If the local authority want you to go back to the unit, you may be able to stop this by asking for a care and treatment review to challenge the decision. You can also seek legal advice.



As set out above, there are two ways you can legally go into the unit against your will. This is under the **Mental Health Act** or the **Mental Capacity Act**.

If you have a mental health condition or very challenging behaviour, two doctors must assess you and recommend that you go back to the unit.

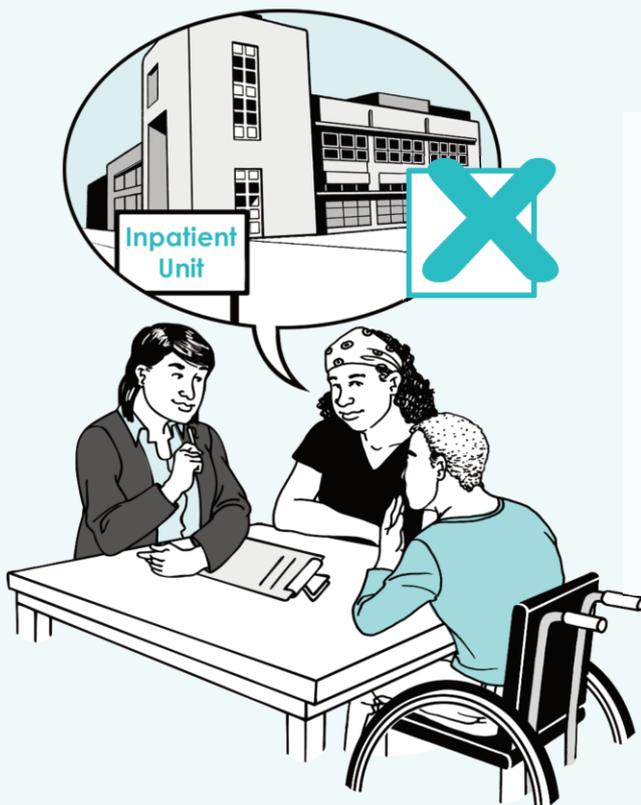
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2



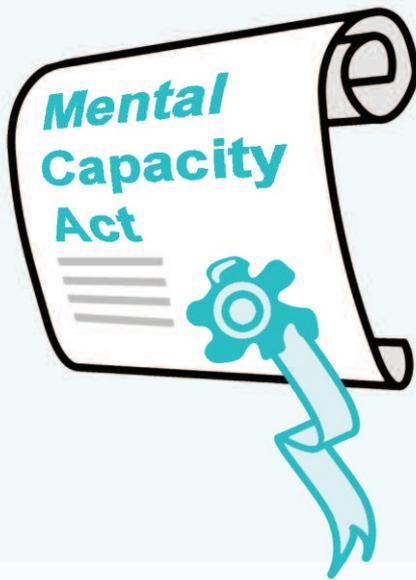
They should tell you the reasons why you should go into the unit.



If you do not agree with the reasons for returning to the unit you should speak to a mental health solicitor as soon as possible for advice.



More details of how to do this start on [page 148](#) of this pack.



Inpatient Unit

If it has been decided you cannot make decisions for yourself, you might be sent to the unit under a law called the Mental Capacity Act, because people think it is in your best interests to be in the unit.



The local authority will have to assess you before you can be sent to the unit.



If you disagree, and think you are able to make your own decision and shouldn't be in the unit you should contact a community care solicitor.



You can search at [solicitors.lawsociety.org.uk](https://solicitors.lawsociety.org.uk) to find your local solicitor.



## Raising concerns



**155** Raising concerns  
- contents



**156** What is abuse?



**170** Making complaints



**185** Other ways of getting  
help and support

## What is abuse?



**Abuse** is when someone bullies you and does or says something to you that makes you hurt, upset or frightened.



You may be scared to speak out or to stop them. The person who is bullying you may make it hard for you to report it.



If abuse happens to you or someone you know it is important to speak out and tell someone that you trust. Do this as soon as you can.

## There are lots of different kinds of abuse:



**Physical Abuse** – this is when someone hurts you by hitting you, kicking you or burning you. It may also be when someone holds you down.



**Sexual Abuse** – this is when someone touches your body and does things to you that you do not like or want them to do.



Sexual abuse is when someone makes you do sexual things that you do not want to do.



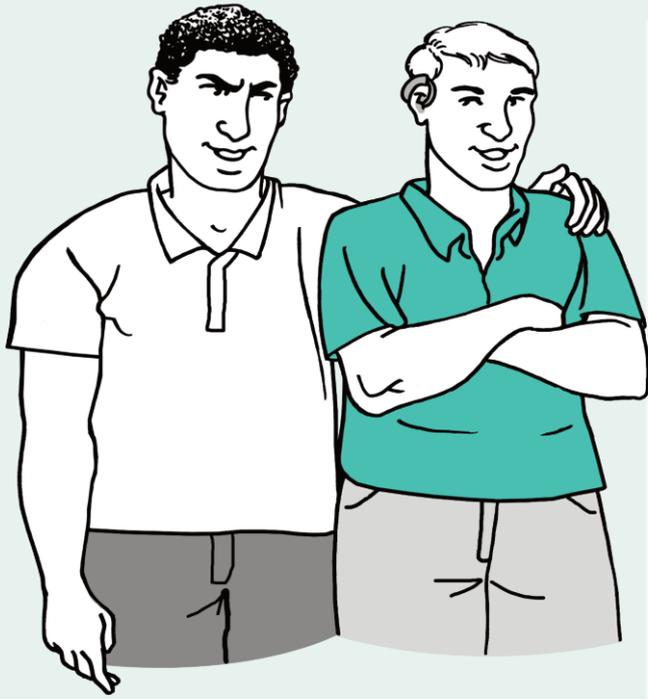
**Emotional Abuse** – this can be when people say bad things to you like teasing or threatening or bullying you to upset you.



It can be when people do not listen to you or do not believe what you say.



**Financial Abuse** – this is when someone takes your money. It is when you do not have a say in how someone spends your money.



### Mate Crime or Tricky Friends

This is when people who you think are your friends take advantage of you. They may get you to pay for everything all of the time.



**Abuse of things that belong to you** – this is when someone takes your private things without asking you.



**Abuse of your rights to choose** the medical care you get such as giving medication against your will.



**Neglect** – this is when people say they are going to help you but they don't. Neglect could be not taking you to the Doctors or not giving you your medicine.



Neglect could be when someone stops you having a social life.



Neglect could be if someone does not support you to keep clean and comfortable.



Neglect could be if someone stops you having enough food or drink.



Neglect can be when people fail to treat you as an equal by not thinking about your feelings and dignity.



**Discrimination** – this is when people say bad things to you or treat you unfairly because you are different from them.



You may be made to feel different because you have a different religion, look different or speak a different language.



You may be made to feel different because you are a disabled person.



You may be made to feel different because of your sexuality. Like being gay, lesbian, bisexual or transgendered.

*Abuse can happen anywhere, at any time. It could happen:*



**In your own home or in someone else's home**



**At work**

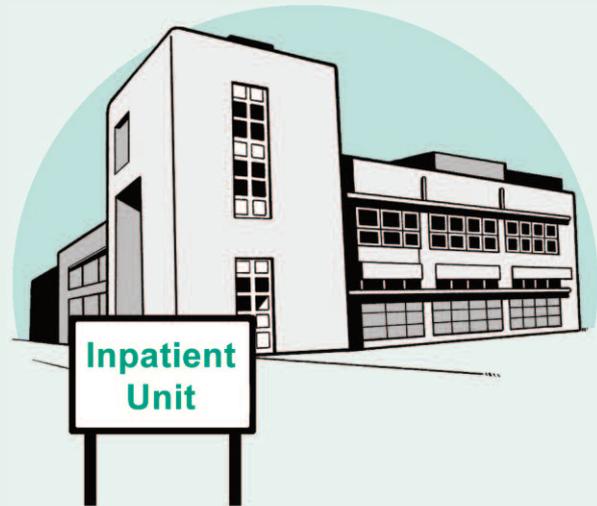


**At your care home**



**At your Day Centre**

**Abuse can happen anywhere, at any time. It could happen:**



**At College**

**In the unit**

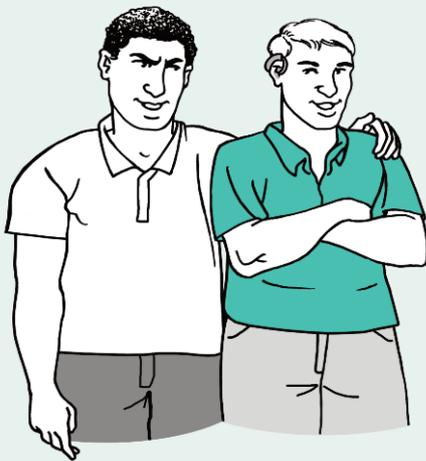


**At your club**

## Who could abuse you?



Most people will not abuse you, but anyone could. It might be someone you know or a stranger.



It could be someone in your family or a friend.



It could be someone who works with you like a social worker or a support worker.

## What should I do if I think I am being abused?



People who are being abused are often scared to speak up.



It is good if you can tell someone you trust, and help to make it stop.



Sometimes the bully can make it hard for you to tell anyone.



**Abuse is not your fault.  
You have a right to have a  
safe life without being  
bullied or abused.**



There are lots of people  
that you could tell if you  
feel you are being abused  
or bullied.



**In an emergency you  
could call the police.**





It is a good idea to take some time to think about who you think you could tell. Write their names and contacts below:



A relative or friend you trust:

-----



A Social Worker you trust:

-----



A member of staff you trust:

-----



## Your Local Safeguarding Board:

-----



## Your Doctor:

-----

## Put other useful contacts here:



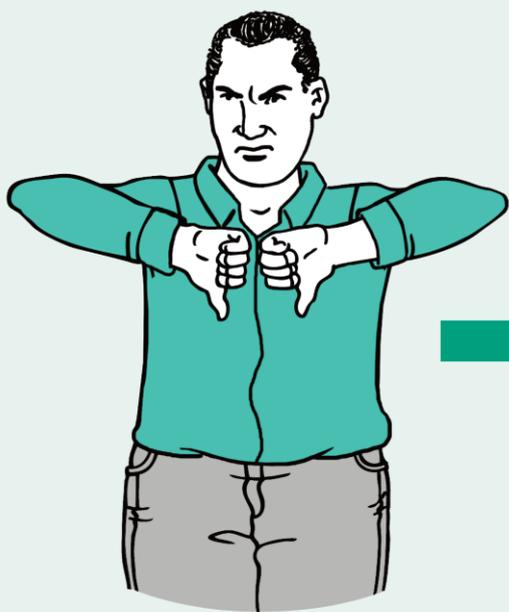
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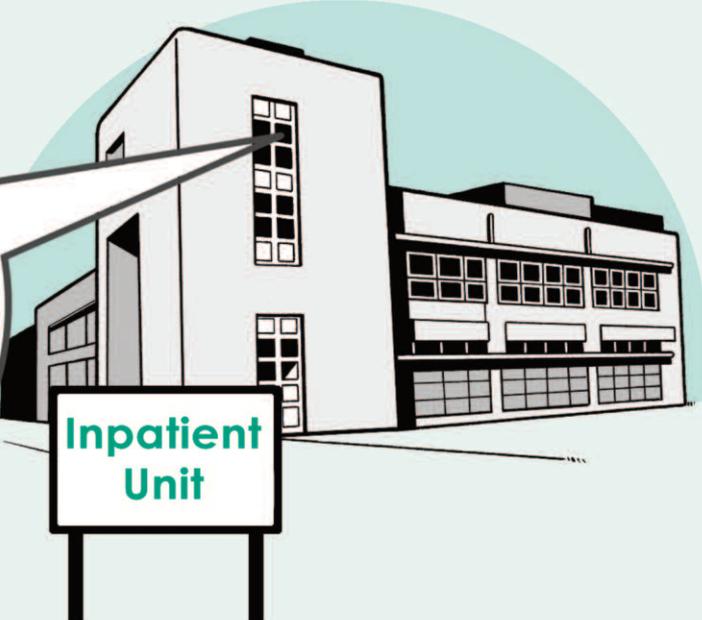
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*I'm unhappy, what can I do?*



Making complaints

If you are not happy with the care you are receiving you can make a **complaint**.



Sometimes things go wrong with our health and social care services.



You have the right to complain about them if you are not happy.



Health and social care professionals can appear very powerful.



If you are worried or anxious about speaking to them, or are worried you will not understand information make sure you have someone you trust with you and who you know will help.

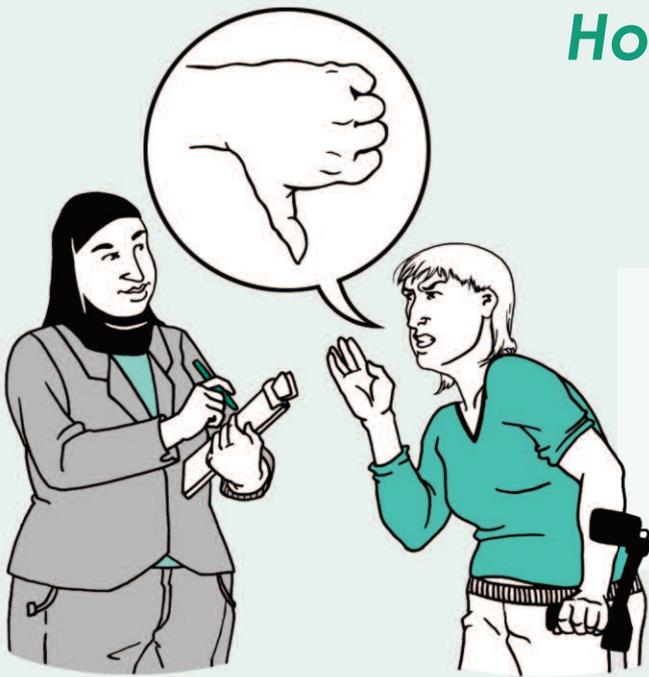


It is a good idea to write down the name of the person you speak to about your complaint. Ask your advocate or a family member to help you with this.



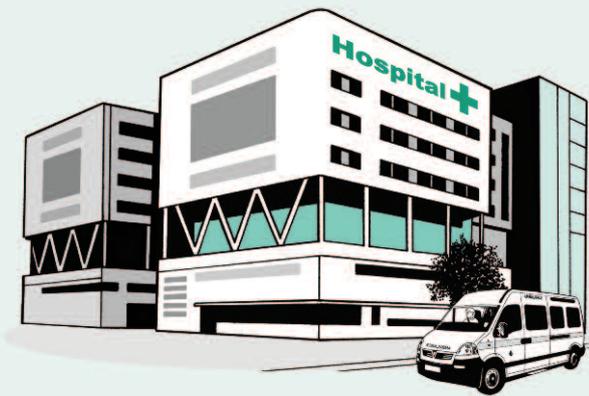
You should also write down what everyone says. Ask your advocate or a family member to help you with this.

# How to complain about NHS Healthcare



If you are not happy with care from an NHS service you can complain.

The NHS service might be the hospital, a doctor or dentist.



You should ask the service to give you a copy of their complaints procedure in a way you understand, and help to explain it to you.



The complaints procedure will tell you how to make a complaint and what happens next.



It will tell you how the NHS service will make changes when they have listened to your complaint.

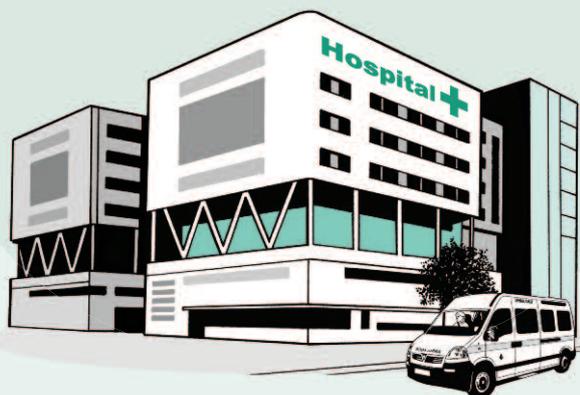


You should complain to the NHS service first so they can try to make things right for you.



If you cannot complain to the NHS service there are other people in the NHS you can complain to.

## If your complaint is about:



A hospital



A local NHS  
community service



You can contact your local NHS Clinical Commissioning Group (CCG). You can find your local CCG on the NHS website: [www.nhs.uk/Service-Search/Clinical%20Commissioning%20Group/LocationSearch/1](http://www.nhs.uk/Service-Search/Clinical%20Commissioning%20Group/LocationSearch/1)

## If your complaint is about:



Your Doctor



Your Dentist



A pharmacy



You can complain to NHS England by calling **0300 311 22 33** or emailing: [england.contactus@nhs.net](mailto:england.contactus@nhs.net)

If you are not happy with the way the NHS deal with your complaint you can contact the Health Service Ombudsman.



It is free to complain to the Health Service Ombudsman and they do not work for the NHS.

They will usually only look at your complaint after the NHS have tried to sort it out first.



## You can contact the Ombudsman:



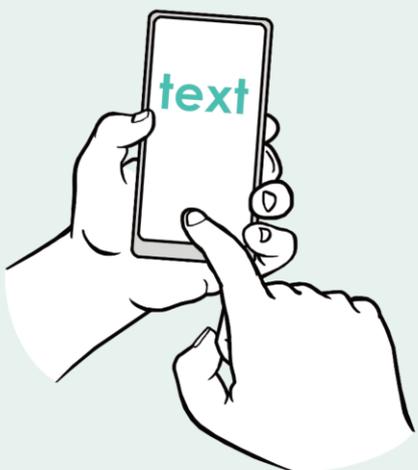
Telephone: **0345 015 4033**



Email:  
**phso.enquiries@  
ombudsman.org.uk**



Textphone: **0300 061 4298**



Text: Text the words **call back** and your name and mobile number to **07624 813 005** and someone will telephone you.



Write to:  
**Parliamentary and Health  
Service Ombudsman  
Millbank Tower  
Millbank  
London  
SW1P 4QP**

## How to make a complaint about your care home or social care service

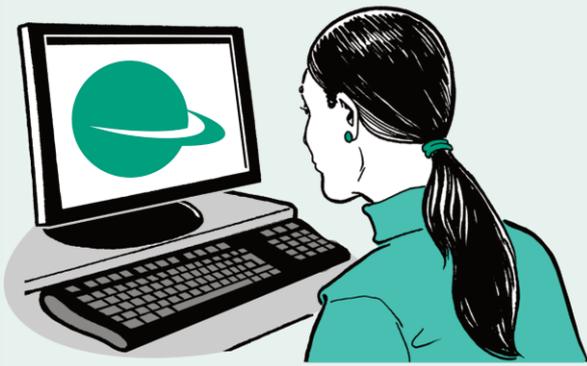
You can also make a complaint about your care home or social care service.



If your care home is paid for by the NHS you should complain in the same way as above.



If you are not happy with the way the NHS has dealt with your complaint you should contact your local council.



You can find their address at this website:

[www.direct.gov.uk](http://www.direct.gov.uk) or you can ask your local **Healthwatch**.



You can also contact the **Local Government Ombudsman** if you pay for your own care or if the local council pays for it.



Telephone: **0300 061 0614**



Write to:

**Local Government  
Ombudsman  
PO Box 4771  
Coventry  
CV4 0EH**

# NHS Complaints Advocacy Service



## My local NHS Complaints Advocacy Service is...

-----

NHS Complaints Advocates can advise and support you if you want to make a complaint about your NHS service.



They can support you to make the complaint and also come to meetings about your complaint with you.



They are free to use and they will keep your information secret.



# Healthwatch

My local Healthwatch Service is...

-----



Healthwatch do not work for anyone else. They listen to people who use the health service and make local services better.



They can help you find more information or support for making your complaint.



You can get more information from their website:

[www.healthwatch.co.uk](http://www.healthwatch.co.uk)

# Care Quality Commission



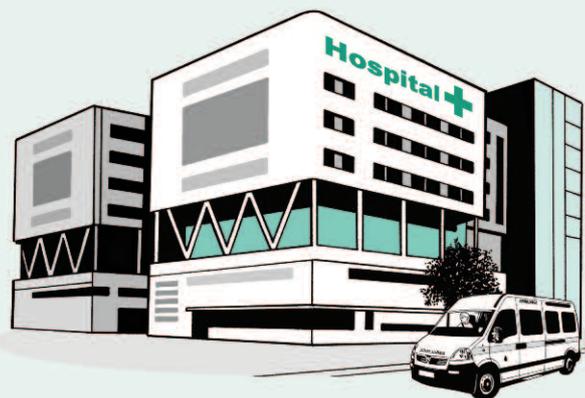
The Care Quality Commission (CQC) does not work for anyone else.



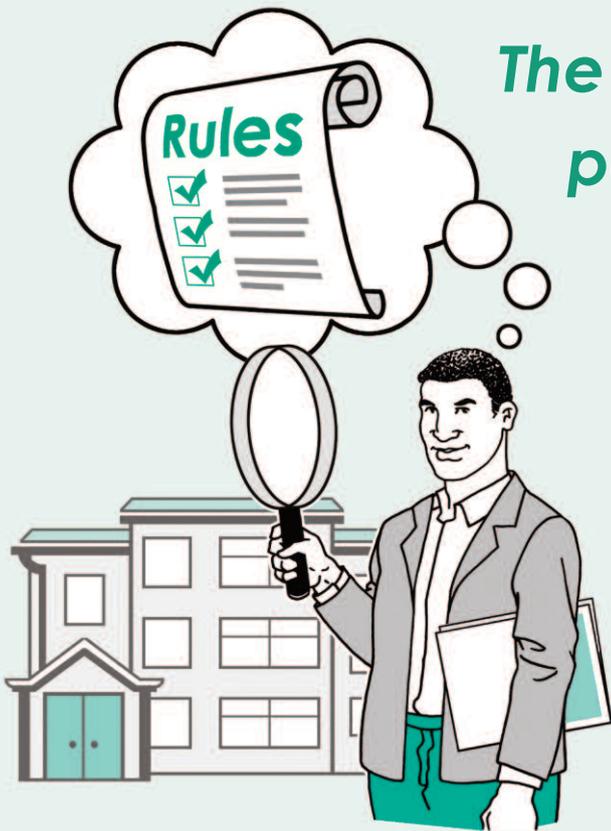
They check services to make sure they are supporting you in the right way.



The CQC have rules so that services keep you safe and give you the right care and support.



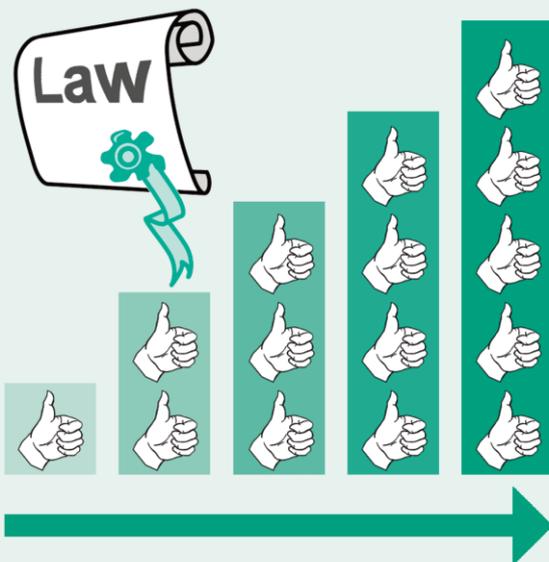
They check lots of services including hospitals, Doctors, Ambulances and Care homes.



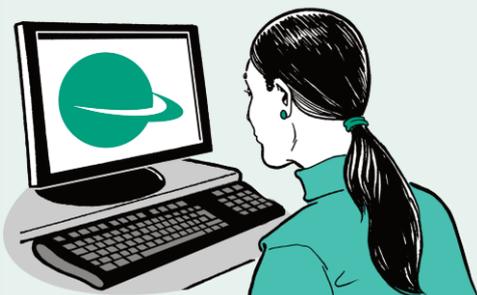
## The CQC will listen to what people say so they can:

Find out which services are not following their rules.

Decide which services to visit and when.



CQC can use the law to make sure services get better when they don't follow the rules.



If you want to tell the CQC about a service even if you don't want to make a complaint:

Telephone: **03000 616 161**

Website: **[www.cqc.org.uk](http://www.cqc.org.uk)**



Other ways  
of getting help  
and support



*If you are unhappy and need more support there are lots of organisations that can help you.*

**The Challenging Behaviour Foundation:**

Information and support on dealing with challenging behaviour.

Telephone: **0845 602 7885** or email: [support@thecbf.org.uk](mailto:support@thecbf.org.uk)

**Citizens Advice Bureau:**

Free and confidential advice on debt, benefits, employment, housing, discrimination and many more.

Telephone: **03444 111 444**

### **DIAL:**

There are around 120 local Disability Information and Advice Line services (DIALs) throughout Great Britain run by and for disabled people.

Telephone: **0808 800 3333**

Website: **[www.scope.org.uk/support/disabled-people/local-advice](http://www.scope.org.uk/support/disabled-people/local-advice)**

### **Disability Living Allowance Helpline:**

The Department for Work and Pensions (DWP) provide a Disability Living Allowance Helpline. The helpline can arrange help filling out claim forms over the phone when you are applying for Disability Living Allowance.

Telephone: **08457 123 456**

Textphone: **08457 224 433**

You can also use the RNID Typetalk service.

The Helpline is open 8.00 am to 6.00 pm Monday to Friday.

### **Disability Law Service:**

They provide specialist legal advice for disabled people, their families and carers on the following subjects: community care and employment.

Telephone: **020 7791 9800**

Website: **[www.dls.org.uk](http://www.dls.org.uk)**

## **Disability Rights UK:**

They have these advice lines:

### **1. Disabled Students Helpline**

Telephone: **0800 328 5050**

(Tues 11.30 – 13.30 & Thurs 13.30 – 15.30)

Email: **[students@disabilityrightsuk.org](mailto:students@disabilityrightsuk.org)**

### **2. Independent Living Advice Line**

Telephone: **0300 555 1525**

Opening hours: Mon and Thurs 9.00 – 13.00

Email: **[independentliving@disabilityrightsuk.org](mailto:independentliving@disabilityrightsuk.org)**

## **Equality Advisory and Support Service:**

Advice on discrimination and human rights issues.

Telephone: **0808 800 0082**

## **Mencap Direct Helpline:**

Advice and information on anything related to learning disabilities.

Telephone: **0808 808 1111** (Monday-Friday 9am-5pm) or

email: **[help@mencap.org.uk](mailto:help@mencap.org.uk)**

### **Mind info line:**

Information and advice on topics about mental health.

Telephone: **0300 123 3393** (Monday to Friday 9am-6pm)

or email: **info@mind.org.uk**

### **Mind's Legal Advice Service:**

Information and advice on legal matters around mental health.

Telephone: **0300 466 6463** or email: **legal@mind.org.uk** for

### **National Autistic Society Helpline:**

Support and advice for people with Autism, they also have a list of law firms who have experience of working with and representing people with autism.

Telephone: **0808 800 4104** (Monday to Friday 10am-4pm)

### **NHS England:**

Lots of information around health can be found on their website: **www.england.nhs.uk/contact-us**

### **Rethink:**

Telephone: **0300 5000 927** (Monday-Friday 10am-1pm) or email: **advice@rethink.org** for mental health information and advice on practical problems.

### **Rights of Women:**

Free and confidential legal advice for women. Including advice on sexual offences including rape and sexual assault, violence and harassment.

Telephone: **020 7251 8887** (Tuesdays 11am-1pm)

### **Samaritans:**

Can help people through tough times, help to understand problems or just be there to listen.

Telephone: **08457 90 90 90** or email: **jo@samaritans.org**

24 Hours a day, 365 days a year.

### **Stop Hate UK:**

A national charity providing independent and confidential support to people affected by hate crime.

Telephone: **0800 138 1624** Website: **www.stophateuk.org**

24 Hours a day, 365 days a year



# Wordbank

# A



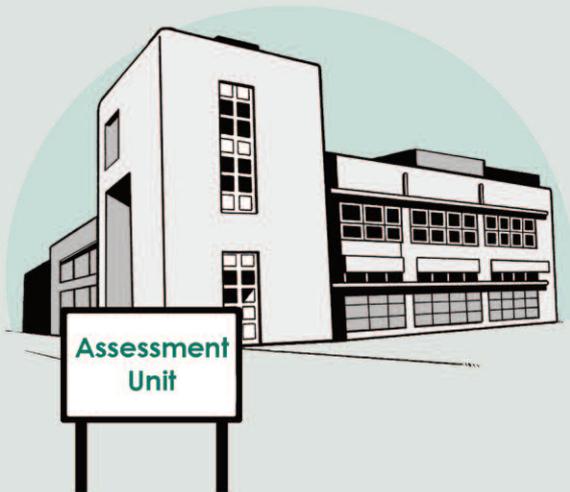
**Abuse** is when someone bullies you and does or says something to you that makes you hurt, upset or frightened.



**Advocacy Services** help people to access information and other services, to make choices and to speak out.



An **advocate** is an independent person who helps you have your voice heard.

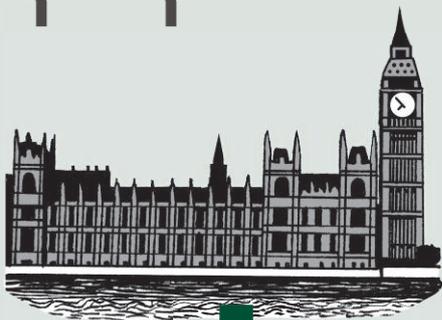


**Assessment and Treatment Units** are types of hospitals for people who have mental health conditions or behaviour that can be challenging.



**B**

**Being sectioned** is when you have been admitted to a unit under the Mental Health Act.



**Benefits money** is money you can get to help pay for things you need. The money comes from the government.

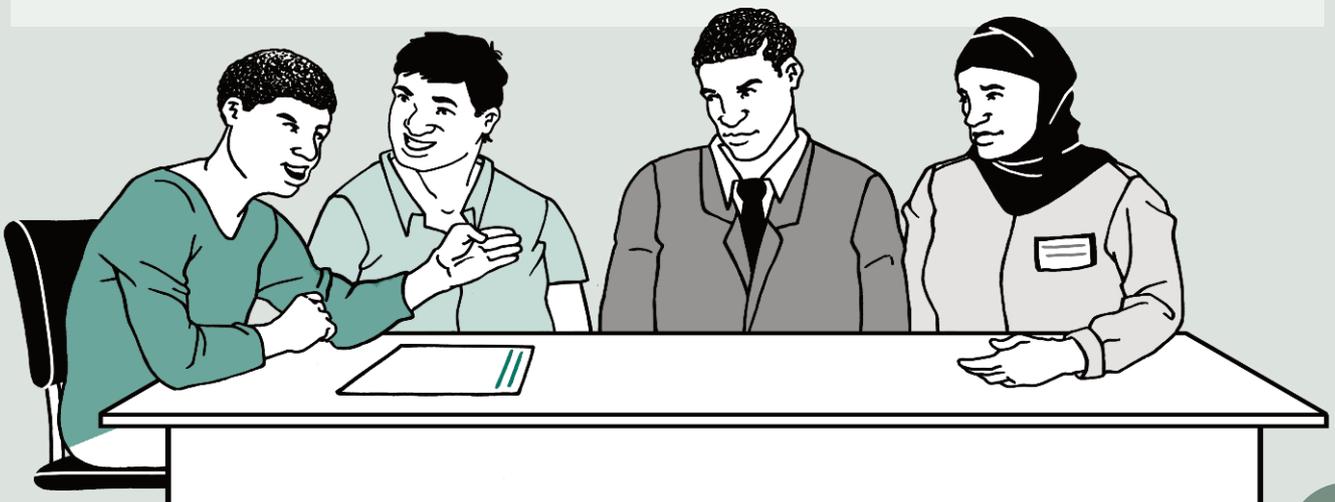


A **carer** will help to support you in your daily life.



In a **care home** you will live with other people with similar needs to you.

**Care Programme Approach** is a way of planning and reviewing your needs to make sure that your treatment, care and support works well together.



## A **Care Programme Approach Coordinator**

(care-coordinator) will make sure that assessment, planning and review happen.



## The **Care Quality Commission** (CQC)

check services to make sure they are supporting you in the right way.



A **Community** is a group of people living in the same place.



A **community learning disability nurse** will support you in the community after you leave the inpatient unit.



A **Complaint** is when you tell someone about something that has happened to you that is unacceptable.



A **Continuing healthcare assessment** is when the NHS find out whether you can receive NHS continuing healthcare. If the decision is Yes a further decision is made on whether you can receive funding.



A **counsellor** will help you talk about your problems and help you learn how to deal with them.



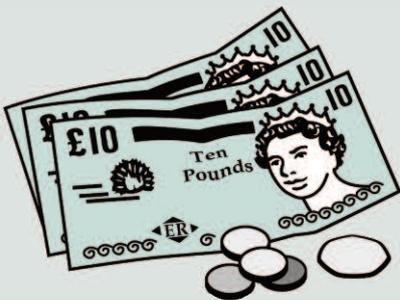
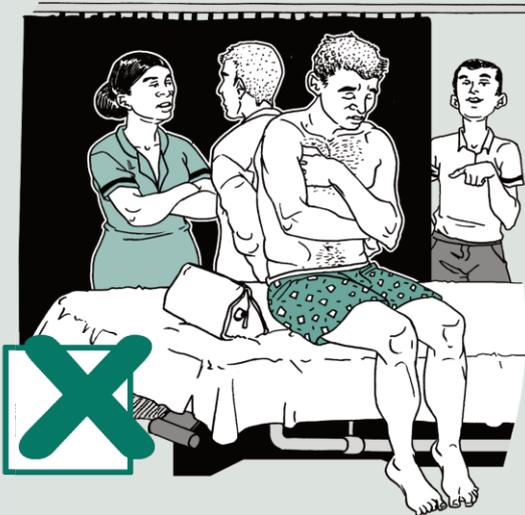
The **Council of Europe** is a group of countries, which came together after the Second World War to stop such terrible acts happening again.



**D**

The part of the government that decides what benefits money you can get are called the **Department for Work and Pensions (DWP)**.

**Dignity** is a sense of pride and self-respect. Everyone is entitled to be treated with dignity.



**Direct payments** are payments of money given directly to you so that you can choose what services to buy and organise your own support.



You are **Discharged** when you leave the inpatient unit to move back into the community.



When you go to the inpatient unit the staff will work with you to make a plan for what will happen when you leave. This is called a **Discharge Plan**.



**Discrimination** is when people say bad things to you or treat you unfairly because you are different from them.

**E**

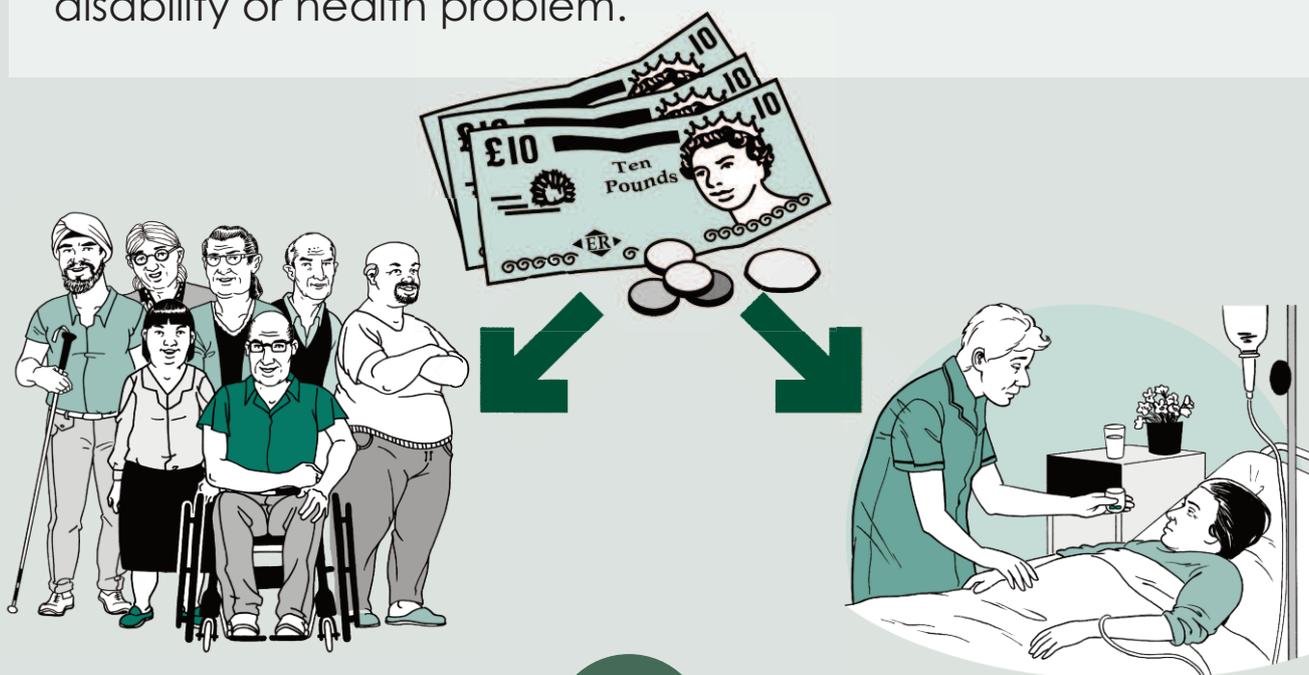


**Emotional Abuse** can be when people say bad things to you like teasing or threatening or bullying you to upset you.



You have a number of rights which are protected by something called the **European Convention on Human Rights**.

**Employment and support allowance (ESA)** is a benefit for people who find it harder to get a job because of a disability or health problem.



**F**

**Financial Abuse** is when someone takes your money. It is when you do not have a say in how someone spends your money.

# H



If you move to supported living you may have a **housing support worker**. They can help you with any problems you have with your housing.

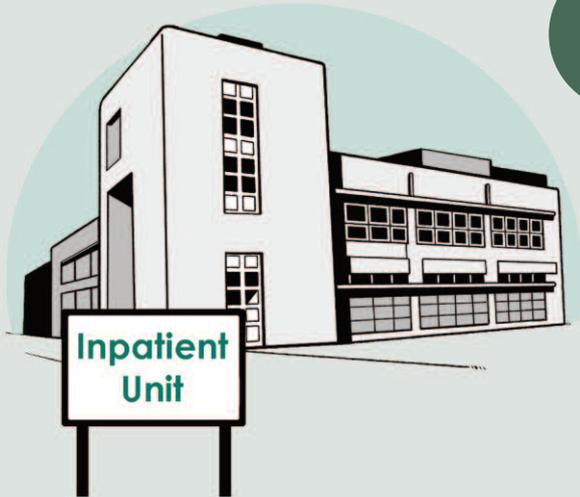


In this country we have the **Human Rights Act** which brings all of the rights in the European Convention on Human Rights into UK law.



If you are not happy with the way the NHS deal with your complaint you can contact the **Health Service Ombudsman**.

# I



**Inpatient units** are types of hospitals for people who have mental health conditions or behaviour that can be challenging.

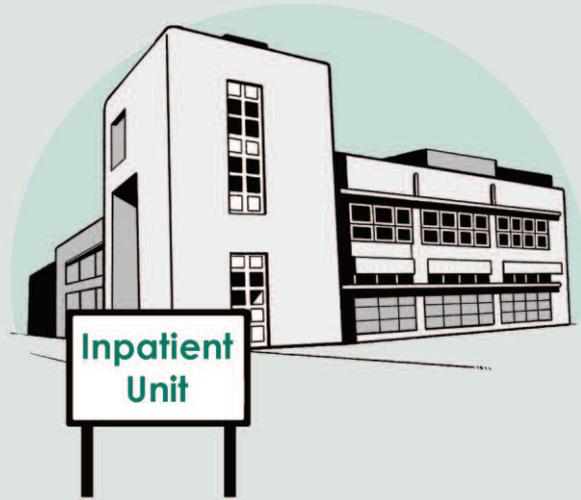


**Independently** is when you think and act for yourself.



An **Independent Mental Health Advocate (IMHA)** can help you find out about your rights in the unit as well as powers being used by professionals involved in your care.

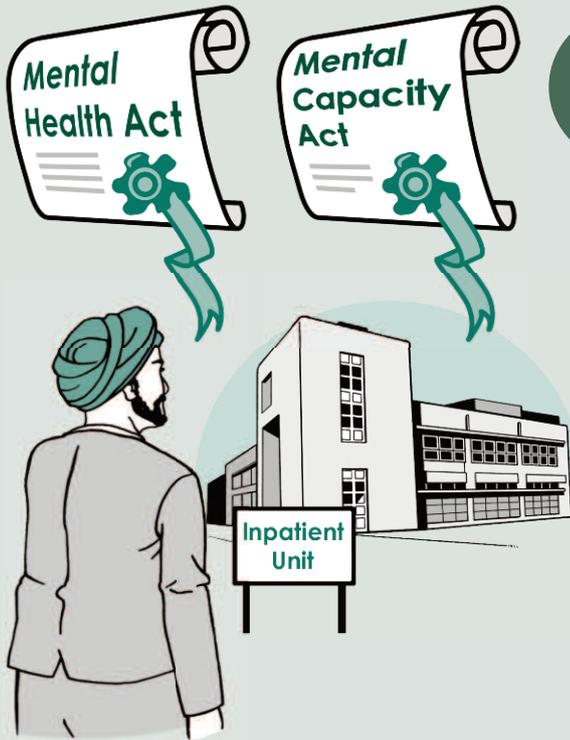
Being in the unit as an **informal patient** means that you have agreed by yourself to spend some time in the unit for assessment or treatment.



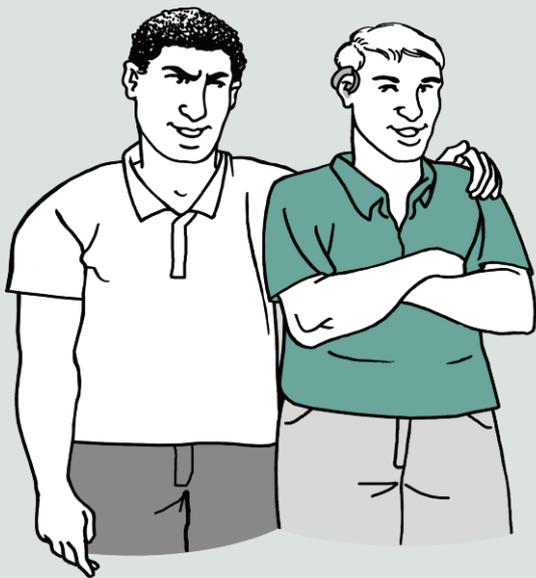
Sometimes people are unable to make decisions about their care or treatment. This is called **lacking capacity**.



A **local authority** is a group of people who are in charge of the public services and facilities in an area.



You can legally go into the unit against your will. This happens under the **Mental Health Act** or the **Mental Capacity Act**.



### **Mate Crime or Tricky Friends**

This is when people who you think are your friends take advantage of you. They may get you to pay for everything all of the time.



You can ask for a **Needs Assessment** to be carried out when you leave the inpatient unit if you need extra support.



**Neglect** is when people say they are going to help you but they don't. Neglect could be not taking you to the Doctors or not giving you your medicine.



**National Health Service** (NHS) is a free healthcare system for everyone in the UK paid for by taxes.

**NHS**



**NHS Clinical Commissioning Groups** are NHS organisations that are led by GPs to buy health services for people living in their area.

**NHS Continuing Care** is a package of care arranged and funded by the NHS, for people who are assessed as having a primary health need.



A **personal budget** is money which is given to you by the local authority or the NHS.



**Personal Independence Payment (PIP)** is money given to disabled people to help with the extra things they need because of their disability.



**Physical Abuse** is when someone hurts you by hitting you, kicking you or burning you. It may also be when someone holds you down.



A **Psychiatrist** is a type of doctor who helps to treat Mental Health Conditions.



A **psychologist** will help you talk about your problems and help you learn how to deal with them.



A **public organisation** is run by the government e.g. the police or the NHS.



**R**

A **right** is something you are allowed to do. The Government and all your public services must respect your rights.



Sometimes staff may stop you doing something you want to do. Sometimes they may make you do something you don't want to do. These are known as **restrictive practices**.



S

**Sexual Abuse** is when someone touches your body and does things to you that you do not like or want them to do.



**Self-advocacy groups** are a way of meeting new people and learning new skills so that you can stand up for your rights.



A **social worker** is a person who will come and visit you in the community and make sure you have everything you need and that you are safe.



A **solicitor** is a legal representative who you can go to for legal advice.



**Supported living** is where you live on your own or with two or three other people. You will have staff in your home to give you any support that you need.

**Treatment** is the management and care of a person.





This easy read pack was produced by **CHANGE**.

**CHANGE** is a leading national Human Rights organisation led by disabled people. We work for equal rights for all people with learning disabilities.

The **Winterbourne View Joint Improvement Programme** commissioned **CHANGE** to produce this easy read pack and we also received support to complete it from **NHS England, Local Government Association** and **ADASS**, the Association of Directors of Adult Social Service. This pack supports ongoing work to change the way that care and treatment are provided so that people spend less time in hospital and receive the care and support they need to live well in the community.

You can call **CHANGE** on **0113 242 6619**,  
email **info@changepeople.org**,  
or find us at **www.changepeople.org**

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