

Good health care for all

What can I expect from the NHS?



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foundation for
people with
learning disabilities

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Made with Photosymbols



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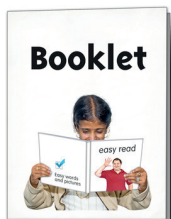
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About this book

This book is for people with learning disabilities, family carers and anyone who supports a person with learning disabilities.



This book is to help you get a good service from the National Health Service (the NHS).



GP Surgery



Hospital

The book is mainly about health services for people who are aged 18 or more. It is mainly about services from your family doctor (**GP**) and hospitals.



Some health services are just for people with learning disabilities. They are usually in the **Community Learning Disability Team**. You can get good information from them. You may be able to get extra help from them if you need it.

You might look at the book on your own. Or you can ask someone to look at the book with you and talk about what it says.



You can look at everything in the book. Or you can look at one bit that is right for you.



Some words to do with health and the NHS are a bit hard. Harder words are shown like this: **NHS Constitution**.



There is a list of these words at the back of the book to tell you what each word means.

NHS What is the NHS?



Some words to do with health and the NHS are a bit hard. Harder words are shown like this: **NHS Constitution**. There is a list of these words at the back of the book to tell you what each word means.

The NHS is made up of lots of different services. For example:



- your family doctor (**GP**) and practice nurse – where you can get health checks and treatment when you are ill



- optician (**optometrist**) – where you get eye tests and glasses (spectacles)



- dentist – where you get your teeth and mouth checked



- chemist (**pharmacist**) – where you can ask for health advice and get some medicines like headache tablets

Here are some other NHS services your doctor or nurse might arrange for you:



- **health promotion** – where you can get advice to help you with healthy living



- **screening** services – you might get asked by your doctor to have a special check that can find an illness like cancer very early, so it can be treated



- community health services like the **district nurse**, **podiatrist** (foot care), **Macmillan nurse** (cancer)



- **audiology** – where you can get your hearing checked and get hearing aids



- services that just work with people with learning disabilities, like the **Community Learning Disability Team** – the team often includes health staff like **learning disability nurses**, **physiotherapist**, **occupational therapist**, **speech and language therapist**, **psychologist**, **psychiatrist**



- mental health services (**psychiatrist**, nurse or **psychologist**) – help if you have a mental health problem



- hospitals – where you go to have special health tests or see different doctors. Or you might have to stay in hospital for extra help



- children's health services – school nurse, children's doctor (**paediatrician**), mental health services for children and young people (**CAMHS**)



- '**transition**' teams for young people who are nearly adults – some areas have a special transition nurse if you have lots of different health needs



All these services work under the **NHS Constitution**. This helps to make health services better and fair for everyone. You can get more information about the **Constitution** from this website: <http://tinyurl.com/cgveofa>



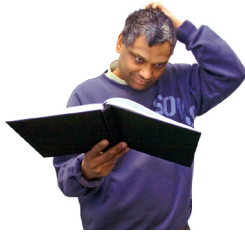
The NHS has to follow the laws about being fair to everyone (the Equality Act 2010). For example, the NHS must try to make it as easy for disabled people as anyone else to use health services. This is called 'making **reasonable adjustments**'. You can find more information from this website: <http://tinyurl.com/cpvw6gx>

The rest of this book has lots of ideas about **reasonable adjustments** you can ask for.

If you need some extra help, please ask someone!



Looking after your health



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There are lots of things you can do yourself to look after your health. For example:



- eating healthy food (like salads and vegetables)



- taking exercise (like having a walk every day)



- not smoking or drinking too much alcohol



- getting health checks with your doctor, dentist and optician at least once a year



- looking after your feet, especially if you have a health problem called diabetes



- looking after the shape of your body (**posture**)



- cleaning your teeth at least twice a day



- having a good wash every day (like a bath or a shower)



It is important for family carers to look after their health too, including carers who have learning disabilities

You can get help from the NHS to keep healthy. Here are some ideas about things you can ask for:



- information in easy read



- information about groups you can join, like walking exercise groups and groups to help people lose weight



- information about where people with learning disabilities can go for dentists and opticians



- regular checks of your ears if you get a lot of earwax



- information in big print and easy read about any medicines you have to take



You can get a health check every year from your family doctor and practice nurse. This is a good idea to help you keep healthy. You can ask for a health check if you have not had one. A health check includes things like:

- checking how tall you are and how much you weigh
- tests for common health problems like high blood pressure
- checking for different illnesses
- checking what medicines you take.



Lots of people like to have a **Health Action Plan**. If you have not got one, you can ask the **Community Learning Disability Team** about them. A **Health Action Plan** holds all the things that are important about your health. It also holds information about things you might do to keep you healthy. For example, you might decide you want to lose some weight. Then you would put in your **Health Action Plan** how you are going to do that and who will help you.



Lots of places have a person called a **Primary Care Liaison Nurse**. (Sometimes they are called a **Health Facilitator**). They may work in the **Community Learning Disability Team**. You can ask them to help you to think about your health. You can also ask them for help with getting health care, from your doctor or the hospital.

Here is an example of a **Health Action Plan**:



Sharifa's **Health Action Plan**

Sharifa has a health problem called diabetes. Her plan says:

- I will not eat sweets or cakes. My friend Hanifa will help me to stay away from those shelves in the shop
- I will get some easy read information on healthy eating for people with diabetes. The diabetes nurse will help me with this
- The diabetes nurse will make sure I get my blood, feet and eyes checked regularly
- Sue, the practice nurse, will help me make all these appointments. She will text me the day before each appointment to remind me to go
- The diabetes nurse will help me join a group of other people who have diabetes so we can support and learn from each other.



Sharifa helps to look after her mum, who has diabetes too. So Sharifa's plan also says:

- I will make a plan with Sue, the practice nurse, for things I need to do to help my mum keep healthy
- Sue will help me ask for a **carer's assessment** from Social Services.

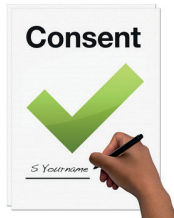
Websites where you can get more useful information

- Lots of easy read information about health:
www.easyhealth.org.uk
- Information about eyes:
<http://www.lookupinfo.org/>
- Information about healthy eating (not easy read):
<http://tinyurl.com/cvjr2p6>
- Information about **Health Action Plans**:
<http://tinyurl.com/dymv5c6>
- Information about looking after body shape (**posture**):
<http://tinyurl.com/cb898km>
- Lots of information about health and health care:
NHS Choices website (not easy read)
<http://tinyurl.com/c38t54>
- Information about health checks: Health Screening Template Part one
<http://tinyurl.com/ckzowyf>



Making decisions about your health

'Mental capacity' means being able to make decisions for yourself. There is a law called the **Mental Capacity Act**. It says you should get help if you need it to make a decision for yourself.



A doctor or another health worker might ask you to **consent** to some treatment for your health. This means asking you to say yes or no. You can do this if you can make the decision yourself.

Sometimes it is very hard to make a decision yourself about your health. You might need a doctor or another health worker to make a decision for you.



If a doctor or another health worker makes a decision for you, they must make a decision in your **'best interests'**. This means doing what is right for you.

They should talk to you and to people who know and care about you to find out what is right for you.

There is an easy read leaflet about the **Mental Capacity Act**. You can get it from this website:
<http://tinyurl.com/c5h9e2v>



Using the NHS



Some words to do with health and the NHS are a bit hard. Harder words are shown like this: **NHS Constitution**. There is a list of these words at the back of the book to tell you what each word means.



There are some important things that people with learning disabilities say about using any bit of the NHS. And there are some things you can ask for that might help you! It is your right to ask for help like this. Services should try hard to make changes like these. They are called **reasonable adjustments**. These are just a few ideas. Maybe they will get you thinking of more things that would help. It is a good idea to tell them you have a disability, so they know you might need some extra help.

You can get an easy read book called “Questions to ask when you go to the doctor or to a hospital”. You can get it from this website:

<http://tinyurl.com/6e4nknd>

Lots of family carers and carers with learning disabilities also say:

- Health staff try hard to listen to the person with learning disabilities. That is good, but they need to listen to me too. Sometimes I know things about my son or daughter that the doctor needs to know.

It may help to write things down before you see the doctor or nurse.



Things people say are hard

I cannot understand the letters they send me



It is difficult to make an appointment. The phone system is too hard! And I cannot use the computer



The receptionist is not very helpful



I find waiting difficult. If I come at the right time, I do not want to have to wait in a crowded room



I sometimes miss my appointment time because I do not hear the receptionist call my name. There are lights that flash too, but I do not know what they mean

Ideas that might help you

Ask them to use easy read when they write to you. Or you could ask them to phone you or send a text message

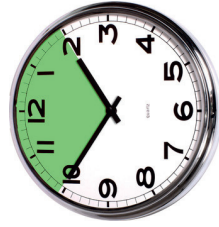
Ask if there is a phone number you can ring that goes straight to the receptionist

Before you go, think about what you want to say. Be polite but firm. Ask them to help or ask someone to help you write down what you want

Ask if you can have the first appointment, or the last one when most people have left. Ask if there is somewhere private you can wait

Ask the receptionist to come over and tell you when to go in

Things people say are hard



Everyone is in too much of a hurry. I need some time to think what to say

Ideas that might help you

Ask for a longer appointment, maybe at the end of the day. This is called a “double appointment”



They do not have the right equipment to help me in and out of my wheelchair

Ask them to make sure they have the right equipment. Write down what equipment you need so they know what to have ready

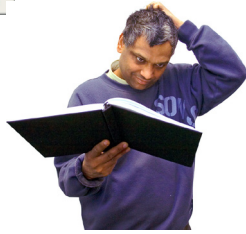


I have asked for help, but nothing has changed

Tell them the law says they should make ‘**reasonable adjustments**’ for disabled people.
Ask for a leaflet about ‘how to complain when you are not happy’. Remember, you can ask for this in easy read!



Going to the doctor or nurse



Some words to do with health and the NHS are a bit hard. Harder words are shown like this: **NHS Constitution**. There is a list of these words at the back of the book to tell you what each word means.



There are some important things that people with learning disabilities say about going to the doctor or nurse. And there are some things you can ask for that might help you! It is your right to ask for help like this. Services should try hard to make changes like these. They are called **reasonable adjustments**. These are just a few ideas. Maybe they will get you thinking of more things that would help. It is a good idea to tell them you have a disability, so they know you might need some extra help.

You might like to look first at the ideas about using any bit of the NHS. Some of those ideas might help with going to the doctor – like making an appointment.

You can get an easy read book called “Questions to ask when you go to the doctor or to a hospital”. You can get it from this website:

<http://tinyurl.com/6e4nknd>

Things people say are hard

It is a bit scary going to the doctor



Ideas that might help you

Ask if you can visit the surgery (where the doctor works) when it is quiet.

You could look at the room where you will see the doctor.

You could look at equipment like:

- the machine that the nurse uses to check your blood pressure
- scales to check your weight
- the bed the doctor may ask you to lie on to look at part of your body

I really cannot go to the surgery. It is too difficult for me



You may be able to ask the doctor to visit you at home. It is not easy for them to do this. They will only agree if it is really difficult for you to go to them because of your health problems or disability

The doctor speaks to my mum or my support worker instead of me. They do not try to understand what I have to say



Before you go, think about what you want to say. You could take your **Health Action Plan** to show the doctor. Be polite but firm – you could say: “I am the one you need to talk to”

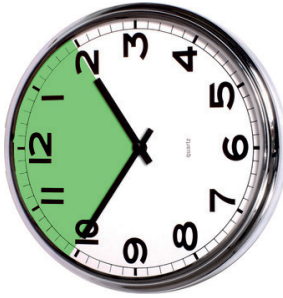


Things people say are hard

The doctor speaks too fast and uses long words

Ideas that might help you

Ask them to slow down and use easy words.
Ask for information in easy words to take away, so you can take it in at your own pace



I need a longer time to say what I want to say and to understand what the doctor is saying

Ask for a longer time ("double appointment") when you make your appointment.
Ask for information in easy words to take away, so you can take it in at your own pace



Sometimes there are things I want to ask that are private. I do not want to ask while my mum is there

Ask to see the doctor or nurse on your own. You can agree with them what will be kept private



Every time I go, I see a different person. I have to explain all over again

Ask to see the same doctor or nurse each time. You could take your **Health Action Plan** to show them too

Here is an example of making an agreement with your doctor:



Earl's agreement with his doctor's surgery

It is important for Earl to know exactly what is happening. Earl gets very upset if he has to wait without being kept informed. Earl's support worker helped him make an agreement with the doctor's surgery. This helps Earl know what to expect, and also what he needs to do:



- You will give me an appointment the same day or the next day if you can. If you cannot do this, I will know you have done your best

- You will tell me exactly what time to come. I will be there. You will do your best to see me at that time. If you cannot do this, you will tell me how long I have to wait. I will do my best to keep calm

- You will try to make sure I see the same doctor each time

- You will give me time to say what I need to say or to ask questions. I may ask my support worker to say some things for me

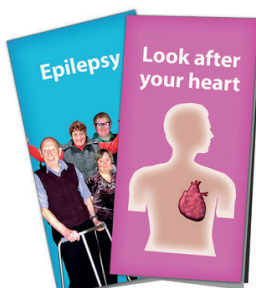
- I will bring my **Health Action Plan** to remind you what is important to me

- If you need to talk to my mum about my health, you will ask me first and tell me why you need to do this

- You will talk to me and use easy words

- You will ask if I would like to take information away with me, in easy words

- You will tell me what will happen next



Lots of family carers and carers with learning disabilities also say:

- The doctor and nurse try hard to listen to the person with learning disabilities. That's good, but they need to listen to me too. Sometimes I know things about my son or daughter that the doctor needs to know
- **My son or daughter can decide some things, if they are explained very carefully. Or a big decision might have to be made by the doctor, after talking to all of us who know my son or daughter well. This is called 'best interests'. Sometimes I have to remind the doctor about the Mental Capacity Act.**

You can get more information about the Mental Capacity Act at this website:
<http://tinyurl.com/bvueljs>

Here is a link to a flowchart about 'best interests' decisions:
<http://tinyurl.com/cc96w4f>

Family carers can ask their son or daughter's doctor or nurse to include them properly. This might mean having an appointment at a time that is right for the family carer.

Lots of doctors and nurses also say:

- It's really hard to know what to do if a person with learning disabilities can't tell me what's wrong and the support worker is from an agency and doesn't know anything!
- I'm not sure if I explain everything well enough, so the person will know what to do
- I'm not sure how much to tell the person's family or support workers
- I'd like some help to find easy read information about common health problems

Doctors and nurses can ask their local **Community Learning Disability Team** or Learning Disability **Primary Care Liaison Nurse** for help. There is easy read information about common health problems at these websites:

www.easyhealth.org.uk

<http://tinyurl.com/5rkdcvf>

www.changepeople.co.uk



Going to hospital for an appointment



Some words to do with health and the NHS are a bit hard. Harder words are shown like this: **NHS Constitution**. There is a list of these words at the back of the book to tell you what each word means.



There are some important things that people with learning disabilities say about going to hospital for an appointment. And there are some things you can ask for that might help you! It is your right to ask for help like this. Services should try hard to make changes like these. They are called **reasonable adjustments**. These are just a few ideas. Maybe they will get you thinking of more things that would help. It is a good idea to tell them you have a disability, so they know you might need some extra help.

You might like to have a **Hospital Passport**. This is a book to hold important information about you and your health. Sometimes the book is called different things (like Hospital Book or Patient Passport). You can see some **Hospital Passports** on this website: <http://tinyurl.com/bmtzbdz>

You might like to look first at the ideas about using any bit of the NHS. Some of those ideas might help with going to hospital – like asking for easy read letters or extra time.

You can get an easy read book called “Questions to ask when you go to the doctor or to a hospital”. You can get it from this website: <http://tinyurl.com/6e4nknd>



Things people say are hard

My own doctor knows me well and knows how to make things easy for me. Will the hospital know this too?



I need to have several different tests, but it is difficult for me to keep travelling to the hospital



It is quite scary going to hospital and having tests

Ideas that might help you

Ask your doctor to tell the hospital what help you need, before you go. You can take your **Communication Passport** or **Hospital Passport** if you have one. (Sometimes these are called different names)

Ask if the hospital has an **'acute liaison nurse'**. This is a nurse who tries to make things in hospital easier for people with learning disabilities. Or you can ask for the **'safeguarding' nurse**

Talk to someone at the hospital before the day of your appointment to let them know if you need any special arrangements

Ask if all the tests and appointments can be on the same day

Ask if you can have help with travel to the hospital

Ask if you can have some information to look at before you go. This could be in easy read, or perhaps a DVD

Ask someone you trust to help you look at the information and think about the questions you want to ask

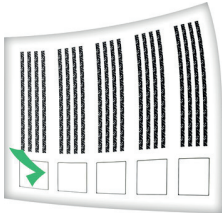
Ask if you can visit the hospital before you go for the proper test. You could ask to see the room where you will be seen, or the machine that might be used for a test

Ask if they can advise you about how to relax. There might be exercises you can do to help you be less anxious

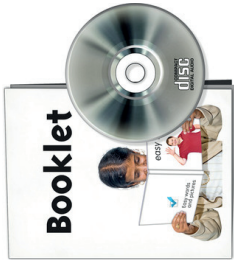


Things people say are hard

It is quite hard to find your way around at the hospital



It can be hard to understand what doctors are talking about



I do not understand the information they send after I have had tests

Ideas that might help you

Ask if there are 'buddies' (people who can help you find your way round). Or visit the hospital before your appointment day so you can figure out how to get around the hospital. Most hospitals have 'help' desks where you can ask for help like this. Ask them before you visit and they may be able to help you to find your way on the day of your appointment

Ask them to slow down and use easy words. Ask for information in easy words to take away, so you can take it in at your own pace
Ask questions about the results of the tests – what do they mean?
Ask questions about the choices for treatment – what is good or bad about them?

Ask for information in easy read
Ask to have someone explain the test results to you

Here is an example about visiting hospital:

Earl's excellent visit to hospital



The doctor said Earl needed to have some tests at the hospital. Earl felt quite nervous about that. His doctor talked to him about the tests and gave Earl some information in easy words and pictures. The doctor said he would write to the hospital and tell them that Earl had a learning disability and would need some extra help.

Earl's support worker, Jason, helped him look at the easy read information and they talked about what it meant. Earl asked Jason to phone the hospital to talk about the help Earl would need. Jason did this and was put through to the **Acute Liaison Nurse**, Ellie. Ellie said she would help make special arrangements for Earl.

The hospital arranged for all Earl's tests to be done on one day. They sent him a DVD with more information about the tests. They sent him a text the day before, to remind him what time to arrive.



When Earl arrived at the hospital he was met by a 'buddy'. This person was a volunteer at the hospital. She helped Earl get to the right places at the right times.



The hospital staff who did the tests all knew that Earl needed some extra help to understand what was happening. They talked to him in easy words. They checked that he agreed to the tests. They let him look around and settle before doing the tests. The last person Earl saw for tests gave him a big card to remind Earl to make an appointment with his own doctor, to talk about the test results.

After all the tests were done Earl's 'buddy' helped him find his way back to the hospital entrance, where Jason was waiting for him. Earl said: "Everything worked right!"

Lots of family carers and carers with learning disabilities also say:

- The doctor and nurse try hard to listen to the person with learning disabilities. That is good, but they need to listen to me too. Sometimes I know things about my son or daughter that the doctor needs to know
- My son or daughter can decide some things, if they are explained very carefully. Or a big decision might have to be made by the doctor, after talking to all of us who know my son or daughter well. This is called '**best interests**'. Sometimes I have to remind the doctor about the **Mental Capacity Act**.

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Staying in hospital



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There are some important things that people with learning disabilities say about staying in hospital. And there are some things you can ask for that might help you! It is your right to ask for help like this. Services should try hard to make changes like these. They are called **reasonable adjustments**. These are just a few ideas. Maybe they will get you thinking of more things that would help. It is a good idea to tell them you have a disability, so they know you might need some extra help.

You might like to look first at the ideas about using any bit of the NHS, or going to hospital. Lots of things people say about going to hospital are the same as they say about staying in hospital. So you can try out some of the same ideas that might help – like asking for easy read letters or extra time.



Things people say are hard

I am really picky about what I eat. I might get upset if I am given the wrong food

Ideas that might help you

You can put this in your **Hospital Passport**, if you have one. (Sometimes these are called different names)

It is a good idea to talk to someone at the hospital about this before you go in to stay. Ask to talk to **PALS** or the **Acute Liaison Nurse**. Or the **‘safeguarding’ nurse**

Take a food plan into hospital

I need people with me who know me well



I need help to eat and drink. If I do not get help, I might choke. Or I might not have any food or drink

You can put this in your **Hospital Passport**, if you have one. (Sometimes these are called different names)

It is a good idea to talk to someone at the hospital about this before you go in to stay. Ask to talk to **PALS** or the **Acute Liaison Nurse**. Or the **‘safeguarding’ nurse**



I know what is important to me, but I need a lot of help to make people understand me

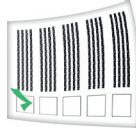
You can have a **Hospital Passport** or a **Communication Passport**. This can tell people about how you tell them what you want. (Sometimes these are called different names)

Things people say are hard

I need a lot of help to understand what is happening



I can make decisions about my health if things are explained with easy read. You need to give me time to understand



I know there are some big decisions that are too hard for me



I need a lot of help with personal care



Ideas that might help you

You can have a **Hospital Passport** or a **Communication Passport**. This can tell people how they should give you information. (Sometimes these are called different names)

You can have a **Hospital Passport** or a **Communication Passport**. This can tell people how they should give you information. (Sometimes these are called different names)

You can ask people who know you well to help the hospital doctors and nurses to make good decisions for you. This is called '**best interests**'

You can put this in your **Hospital Passport**, if you have one. (Sometimes these are called different names)
It is a good idea to talk to someone at the hospital about this before you go in to stay. Ask to talk to **PALS** or the **Acute Liaison Nurse**. Or the '**safeguarding**' nurse

Things people say are hard

I do not feel very safe in a ward with other people



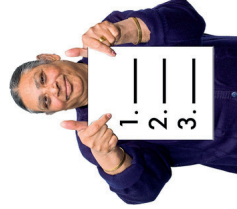
I find being in a noisy ward very difficult. I get upset



It is important that you understand what help I will need when I leave hospital



I want to know what will happen next!



Ideas that might help you

It is a good idea to talk to someone at the hospital about this before you go in to stay. Ask to talk to **PALS** or the **Acute Liaison Nurse**. Or the **‘safeguarding’ nurse**. They might suggest you stay in a “side ward”. This is a room off the main ward

It is a good idea to talk to someone at the hospital about this before you go in to stay. Ask to talk to **PALS** or the **Acute Liaison Nurse**. Or the **‘safeguarding’ nurse**. They might suggest you stay in a “side ward”. This is a room off the main ward

Ask about plans for you leaving hospital. You might need to keep taking some medicine. You might need some extra help at home for a while. You can ask the hospital staff to talk to your family or your support staff about this too.

Ask for information in easy read. If you need to go for a check-up, ask for help to make the appointment

You can get an easy read book called “Questions to ask when you go to the doctor or to a hospital”. You can get it from this website:

<http://tinyurl.com/6e4nknd>

Here is an example about staying in hospital:

Michael's good stay in hospital



Michael was born with a health problem called Tuberous Sclerosis. This means he has quite a few health problems. He has complex epilepsy (fits) and his kidneys are not working properly. Michael does not speak, but he loves to join in with whatever is going on in his noisy family! Michael lives with his family and gets support from two Personal Assistants. Michael's family were worried when they heard he would have to go to hospital and stay there for an operation. Michael had a bad time when he had to stay in hospital before.



This time the **Community Learning Disability Team** asked their **Primary Care Liaison Nurse**, Sam, to work with Michael, his family and the hospital to make a plan for his stay. Sam came to Michael's house to meet him and his family and Personal Assistants. They talked about what had gone wrong last time, and what Michael would need this time. Sam helped them to make a **Hospital Passport** for Michael. They wrote down all the things that were important to Michael, like how to help him relax. They wrote down all the things that were important to keep Michael safe, like how to help him to eat without choking.



Sam went to talk to the **Acute Liaison Nurse** at the hospital. They looked at Michael's **Hospital Passport** together. They talked about all the arrangements that would be needed to make Michael's stay a success. Staff on the ward thought Michael should go into a side room. Sam thought Michael might like the main ward better, as there was more going



on. Staff on the ward were worried that they would not have enough time to support Michael well at important times like mealtimes. Sam said the hospital should pay for one of Michael's Personal Assistants to go in to support him. The hospital did not want to do this at first. The **Acute Liaison Nurse** talked to the **Patient Advice and Liaison Service (PALS)** and persuaded them to agree.

On the day that Michael went into hospital the **Acute Liaison Nurse** met him and his family on the ward. Michael met his 'named nurse' from the ward team. He gave her his Hospital Book. She agreed to tell the other nurses how important it was to support Michael using all the information in his **Hospital Passport**. She agreed to speak to Michael's family every day. She made a plan with Michael's Personal Assistant, to agree who would do what. The Personal Assistant showed her how to talk to Michael while she was working with him.

Before Michael's operation all the doctors and nurses got together to make sure they had a good plan for him. They invited his family and the **Acute Liaison Nurse**. They made sure everyone agreed that the operation was in Michael's best interests. They talked about how to make sure Michael was supported while he waited for the drug (anaesthetic) to put him to sleep before the operation, and while he was waking up after the operation. They talked about what would happen after the operation, and what Michael and his family would need when he went home.



The operation went OK, but that night the nurses were worried about Michael. They called his family and his mum came to the hospital. They offered her a comfy chair by Michael's bed and a cup of tea. They checked during the night to see if she wanted anything else, and made sure she knew where the toilets were. They gave her a pass for the car park. In the morning Michael was a bit better.

The **Acute Liaison Nurse** popped in every day to make sure things were going OK. Before Michael was due to go home she got everyone together again and they went through all the plans. They agreed who would sort out some new equipment



Michael would need at home. They agreed who would speak to the district nurse about checking on him at home. They arranged some training for Michael's family and Personal Assistant about the new equipment. They fixed a date for Michael to come back for a check-up.

Michael's family were really pleased with how this stay in hospital went. They said a big 'thank you' to all the hospital staff.

Lots of family carers and carers with learning disabilities also say:

- The doctor and nurse try hard to listen to the person with learning disabilities. That is good, but they need to listen to me too. Sometimes I know things about my son or daughter that the doctor needs to know
- My son or daughter can decide some things, if they are explained very carefully. Or a big decision might have to be made by the doctor, after talking to all of us who know my son or daughter well. This is called '**best interests**'. Sometimes I have to remind the doctor about the **Mental Capacity Act**
- The hospital seem to assume that I or a support worker will come and look after my son or daughter. They need to talk to us about what is possible and reasonable!
- I have needs as a carer. If I need to stay with my son or daughter, the hospital should help me with parking, somewhere to rest and access to food and drinks

You can get more information about the **Mental Capacity Act** at this website:

<http://tinyurl.com/c8g2bzn>

Here is a link to a flowchart about '**best interests**' decisions:

<http://tinyurl.com/d7w4t6v>

There is a guide for families and hospitals about supporting people with learning disabilities in hospital. You can find it at this website:

<http://tinyurl.com/bwocmba>

Lots of doctors and nurses also say:

- It's really hard to know what to do if a person with learning disabilities can't tell me what's wrong and the support worker is from an agency and doesn't know anything!
- I'm not sure if I explain everything well enough, so the person will know what to do
- I'm not sure how much to tell the person's family or support workers
- I don't know how much I can ask the person's family or support workers to help them while they are in hospital
- I'd like some help to find easy read information about common health problems
- I'm not sure what help the person will get when they leave hospital

Doctors and nurses can ask their local **Community Learning Disability Team** for help. There may be an **Acute Liaison Nurse** in the hospital.

There is a guide for hospitals and families about supporting people with learning disabilities in hospital:

<http://tinyurl.com/bwocmba>

There is easy read information about common health problems at these websites:

www.easyhealth.org.uk
<http://tinyurl.com/5rkdcvf>
www.changepeople.co.uk



How to get help in a hurry



Some words to do with health and the NHS are a bit hard. Harder words are shown like this: **NHS Constitution**. There is a list of these words at the back of the book to tell you what each word means.

Sometimes you need to get help with a health problem in a hurry. Here are some things you can do:



Pharmacy

- You might be able to get some advice from the chemist (**pharmacist**). They might be able to suggest some treatment if they do not think you need to see a doctor



- You could ring NHS Direct to ask for advice: 0845 4647. Or look on their website: <http://www.nhsdirect.nhs.uk/> (not easy read)
In a few places there is a new number you can call (111). It should work everywhere by 2013



- Your doctor's surgery might have a phone number you can call for advice even when the surgery is not open ('out of hours')



NHS
Walk-in Centre

- In some cities there are NHS 'walk in centres' that you can go to any time for health care



- Some hospitals have 'minor injuries units' where you can go for treatment if you are hurt (like if you have cut your finger and it will not stop bleeding)



- You might have to go to a hospital Accident and Emergency Department (A&E) if you are hurt very badly



- If someone has a bad accident, or a sudden bad illness like a heart attack or a stroke, you might need to phone or text 999 for an ambulance. If you need an ambulance, the staff will have to ask you lots of questions.

Good ideas



The London Ambulance Service uses a book called the “Pre Hospital Communication Guide” with easy read pages. You could ask your local ambulance service if they have something like this. You can give them this website address:
<http://tinyurl.com/cnxtwbfb>



If you have a mobile phone, save the telephone number of someone who can be phoned in an emergency. Save the number with the name ICE. This means ‘In Case of Emergencies’. Ambulance staff and police all know what this means.



Some people have health problems that are important to know about in an emergency. For example, some people must not be given a drug called penicillin. People can wear a bracelet or a pendant (‘MedicAlert’) that has details about their health problems.



Who can help you?



Some words to do with health and the NHS are a bit hard. Harder words are shown like this: **NHS Constitution**. There is a list of these words at the back of the book to tell you what each word means.



If you have a question about your health, you can ask a health person you know (like your doctor or nurse).



You can get some advice about health from your chemist (**pharmacist**). And there is more from the website NHS Choices and the phone line NHS Direct. (These are not easy read).



Here are some other ideas about people you can ask:

- **Community Learning Disability Team**: you may already know some people from the Team, like a learning disability nurse. If you don't know anyone there, you can get contact details for the Team from Social Services
- **Health Facilitator**: this is a person who helps you think about your health. They can help you make a **Health Action Plan**. Sometimes they are called different things. You can usually find the right person through the **Community Learning Disability Team**
- **Patient Advice and Liaison Service (PALS)**: every hospital has a **PALS**. They can give you information about health care and the NHS

- **Acute Liaison Nurse**: this is a nurse who tries to make things in hospital easier for people with learning disabilities. Not every hospital has one. You can find out if your hospital has one through the **Community Learning Disability Team** or through **PALS**
- **Safeguarding Nurse**: most hospitals have a nurse who is responsible for making sure that people are safe from harm while they are in hospital
- **HealthWatch**: this service will start in 2012 (it is being tried out in some areas sooner than this). **HealthWatch** will help people get information about health services. They will also collect information about how good or bad local services are.



If you are unhappy about your health care, some services are there specially to help:

- **Patient Advice and Liaison Service (PALS)**: every hospital has a **PALS**. They can help if you are unhappy with the hospital services. They can help you if you want to complain
- **Independent Complaints Advocacy Service**: this service is completely separate from the NHS. They can help you make a complaint. You can get in touch with them through PALS
- **Patients Association**: this is a charity that is quite separate from the NHS. They have a helpline you can call. The number is 0845 608 4455



Where you can get more information

Books Beyond Words: books for people with learning disabilities. Some of the books are about health problems
<http://www.picturesbeyondwords.com>

CHANGE: an organisation that works for the human rights of people with learning disabilities. CHANGE has some easy read information about health
www.changepeople.co.uk

Easyhealth: a website with lots of easy read information about health problems and health care
www.easyhealth.org.uk

Foundation for People with Learning Disabilities: an organisation that works with health services to help them get better
www.learningdisabilities.org.uk

General Medical Council: learning disability resources launched in Spring 2012
www.gmc-uk.org/learningdisabilities

Health checks: Your Say Advocacy Service are launching a DVD about health checks in Spring 2012. Email: info@yoursay-advocacy.co.uk

Improving Health and Lives: a website with lots of information about the health of people with learning disabilities
www.improvinghealthandlives.org.uk

Leeds Animation Workshop: two DVDs and easy read books about going to the doctor and going to hospital
<http://www.leedsanimation.org.uk/index.html>

Look Up: a website with lots of information from SeeAbility about looking after your eyes
<http://www.lookupinfo.org>

Mencap: an organisation that campaigns for better health care for people with learning disabilities
www.mencap.org.uk

NHS Choices: a website with lots of information about health and health care
www.nhs.uk

A picture of health: a website with easy read information about health and health care in South West England
www.apictureofhealth.southwest.nhs.uk/

PRODIGY: a website with lots of information about health problems and health care
www.prodigy.clarity.co.uk

Postural Care Campaign: a web page about how to get better care for people who need a lot of help to protect the shape of their bodies
<http://tinyurl.com/cb898km>

Reasonable adjustments: examples of changes the NHS can make
www.ihal.org.uk/adjustments

Royal College of General Practitioners: learning disability resources for GPs
<http://tinyurl.com/d747vaz>

UK Health and Learning Disability Network: an email network of people all over the country who are interested in the health of people with learning disabilities
www.jan-net.co.uk



What some of the words mean

Acute liaison nurse: a nurse who works in hospital to try to make things easier for people with learning disabilities

Audiology: the service that does hearing tests and can give out hearing aids

Best interests: deciding what is right for a person if they cannot make the decision for themselves

CAMHS (Child and Adolescent Mental Health Service): the service that helps children and young people if they have mental health problems

Carer's assessment: a check to see what help you need if you are caring for another person

Communication passport: a book about how you let people know what you want, and how they should talk to you

Community Learning Disability Team: a team of health workers and social workers who just work with people with learning disabilities

Consent: saying yes or no to a health test or treatment

District nurse: a nurse who helps people at home, like giving an injection

GP: a family doctor

Health Action Plan: a plan about all the things that are important for your health

Health facilitator: someone who can help you think about your health

Health promotion: a service that teaches people about looking after their health

Hospital passport: a book with important information about you and your health that you can take to hospital

Learning disability nurse: a nurse who just works with people with learning disabilities

Macmillan nurse: a nurse who helps people who have cancer

Mental capacity: being able to make decisions for yourself

Mental Capacity Act: the law about making decisions

NHS Constitution: the ground rules for the NHS, to help make health services better and fair for everyone

Occupational therapist: a health worker who helps people learn to do the things they want to do, at home or at work or out and about

Optometrist: a health worker who does eye tests and gives out glasses (spectacles)

Paediatrician: a children's doctor

PALS (Patient Advice and Liaison Service): a service that can give you information about the NHS and help you if you have problems using the NHS

Pharmacist: a health worker who knows about medicines

Physiotherapist: a health worker who knows about how bodies move

Podiatrist: a health worker who knows about looking after feet

Posture: the way you sit, stand or lie. This is important for keeping healthy

Primary care liaison nurse: a nurse who helps family doctors and other nurses to give good services to people with learning disabilities

Psychiatrist: a doctor who knows about mental health problems

Psychologist: a health worker who knows about behaviour and how people's minds work

Reasonable adjustments: changes that the NHS and other services can make, to make it easier for disabled people to use the services

Safeguarding nurse: a nurse who helps NHS services think about how to keep people safe from harm

Screening: tests for cancer

Speech and language therapist: a health worker who helps people who have difficulty speaking or being understood. They also help people who have difficulty swallowing

Transition: moving from services for children and young people to services for adults

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