



# Healthcare for people with a learning disability

Information for people with a learning disability, their families and carers



This document was written by the **Paul Ridd Foundation**. It is an easy read version of 'Access to healthcare information pack'.

**August 2022**

# How to use this document



This is an easy read document. But you may still need support to read it. Ask someone you know to help you.



Words in **bold blue writing** may be hard to understand. You can check what the words in blue mean on **page 31**.



Where the document says **we**, this means the **Paul Ridd Foundation**. For more information contact:

**Website:** [paulriddfoundation.org](http://paulriddfoundation.org)

**E-mail:** [info@paulriddfoundation.org](mailto:info@paulriddfoundation.org)

**Phone:** 01639 820026



This document was made into easy read by **Easy Read Wales** using **Photosymbols**. To tell us what you think about this easy read version, [click here](#).

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# Introduction



This document is for people with a learning disability, their families, and carers.

## It is about:



- healthcare services for people with a learning disability



- the support available to help you get the right healthcare.



People with a learning disability have the right to get good healthcare in a safe way.

# About the Paul Ridd Foundation



The Paul Ridd Foundation was set up to support people with a learning disability, their families, and carers.

## We want:



- **Acute and primary care liaison nurses** in every hospital across Wales. These are nurses with special training to help and support people with a learning disability.



- More people with a learning disability to get an annual health check. All people with a learning disability to have a **health profile**.



- All health boards in Wales to have a computer system that shows when people with a learning disability are in hospital, so staff know how to care for them well.



- Every hospital ward to use the **Care Bundle**. The care bundle says what health staff must do to give the right care and treatment to patients with learning disabilities.



- Learning disability awareness training for NHS staff.



We want to make sure what happened to Paul does not happen to anyone else.



You can read about Paul's story on our website here:  
[paulriddfoundation.org/pauls-story](http://paulriddfoundation.org/pauls-story)

# About Mencap Cymru



Mencap Cymru works to make sure people with a learning disability are:

- valued
- listened to
- and included.



You can use the Wales Learning Disability Helpline if you need:

- advice
- help to access a service
- information about your rights
- support



The helpline is open Monday to Friday and Bank Holidays. Call the Wales Learning Disability Helpline on: **0808 8000 300**



For more information, you can check [wales.mencap.org.uk](http://wales.mencap.org.uk)



# Things you need to know about your healthcare

## Reasonable Adjustments



**Reasonable adjustments** are changes services can make to make sure everyone is able to use them.

For example, putting ramps in buildings for wheelchair users. Or giving information in easy read.



Your GP and hospital must make **reasonable adjustments** for you, so you can easily use their services. It is the law.

Here are some examples of **reasonable adjustments** your GP or hospital can make:

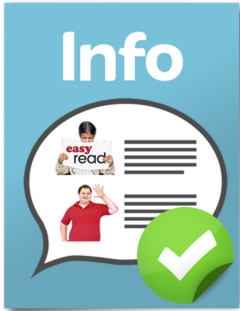


- Giving you an appointment at a quiet time of day. Or giving you a longer appointment.





- Giving you a quiet room to sit and wait when in hospital.



- Sending you easy read appointment letters. And making sure health staff use simple and clear language.



- Inviting you to visit the place you will be getting treatment beforehand.

# Annual Health Checks



This is a health check that happens once a year for people with a learning disability over the age of 18.



You must be on your GPs learning disability register to get an annual health check.



Contact your GP to check if you are on their register. If you are not, you can ask to be added.



If you need help with this, contact your **local community learning disability nursing team**. You can find contact numbers on **page 28**.



The annual health check is a great way to stay healthy.



You should have the health check even if you are feeling well.



You can take someone with you to feel more comfortable. And you can ask as many questions as you want at the health check.

At your annual health check, a doctor or nurse will:



- Check your blood pressure and listen to your heart.



- Ask about what you eat, if you exercise, and about the medicine you take.



- Check your hearing and eyes.



- Talk to you about how you are feeling and if you have any worries.



- They may take blood and urine tests.



- They may ask for more tests if needed.



The doctor or nurse will write a **Health Action Plan** about any health issues you have.



It will say what needs to be done to improve your health. It should give a date for checking if these things have been done.



You will get this action plan at the end of your health check.

# Health Profiles



Your **Health Profile** is a short document that gives health staff information about:

- your health issues
- your likes and dislikes
- how you like to communicate
- your care and support needs.



It will help NHS staff make **reasonable adjustments** for you. To make sure you get care in the best way for you.

A blank 'Health Profile' form. At the top, it has logos for 'GIG NHS' and 'IMPROVEMENT CYMRU'. The title 'Health Profile' is in a dark blue box. Below the title, it says 'This document gives you information that will help you to provide healthcare for me. Please read it carefully and use the information it contains.' There are several fields: 'My name is:', 'I like to be known as:', 'My date of birth is:', 'In an emergency please contact:', and 'Date this form was completed:'. On the right side, there is a large box labeled 'A photo of me can be put here' with a small illustration of a person.

You can get a blank Health Profile on our website here: [paulriddfoundation.org/health-profile](http://paulriddfoundation.org/health-profile)



Download it and fill it in. There is information on how to fill it in on our website.



You can ask for help to fill it in. Ask someone you know.



Take your **Health Profile** to every health appointment. Including emergency appointments and visits to hospital.

GWILLANT CYMRU IMPROVEMENT CYMRU GIG NHS

**Health Profile**

This document gives you information that will help you to provide healthcare for me. Please read it carefully and use the information it contains.

My name is: \_\_\_\_\_

I like to be known as: \_\_\_\_\_

My date of birth is: \_\_\_\_\_

In an emergency please contact: \_\_\_\_\_

Date this form was completed: \_\_\_\_\_

Keep your **Health Profile** updated. If anything important to your health changes write it in.

# Acute Learning Disability Liaison Nurses



**Acute Learning Disability Liaison Nurses** are nurses with special training to help and support people with learning disabilities.



They will be your main contact if you have to go into hospital. They will support you and make sure you have a good experience when you are in hospital.



When Paul died, there were only **2 Acute Learning Disability Liaison Nurses** across Wales.



There are now 19 across Wales. We are really happy about this. But we still want there to be more.





Please tell us about your experience with the Acute Learning Disability Nurse service. Good or bad. We want to hear your stories. It will help us to make things better.



Contact us if you need to know how to get in touch with the **Acute Learning Disability Liaison Nurse** for your hospital:

**E-mail:** [info@paulriddfoundation.org](mailto:info@paulriddfoundation.org)

**Phone:** 01639 820026

**Website:** [paulriddfoundation.org/resources-for-patients-families-carers](http://paulriddfoundation.org/resources-for-patients-families-carers)



In an emergency, if you cannot get through to us, please contact the **Wales Learning Disability Helpline** on **0808 8000 300**.

# Learning Disability Champions



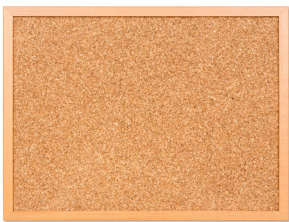
Learning Disability Champions are there to support you and your family when you are in hospital.



They will help make any **reasonable adjustments** you may need.



They will remind other healthcare staff that you might need some extra support.



You can check the noticeboard on your ward for who is the ward champion. If there is no information there please let us know.



We have trained over 2,000 learning disability champions within hospitals in Wales. More champions are trained every month.

# What to do if you are feeling unwell

## NHS 111 Wales



NHS 111 Wales is a free phone service. It is open all day, every day.

### Call NHS 111 if you:



- are feeling unwell and you do not know what to do.
- want information on different health conditions and local health services.
- need your doctor but the surgery is closed.



There is also lots of information on the NHS 111 Wales website. Including Easy Read information, which you can find here: [111.wales.nhs.uk/easyreads](https://111.wales.nhs.uk/easyreads)

# Calling 999



Call 999 in a medical or mental health **emergency**. This is when someone is seriously ill or injured and their life is at risk.



If you phone 999, the ambulance service will ask you questions to find out:

- what is wrong
- and how serious your problem is.



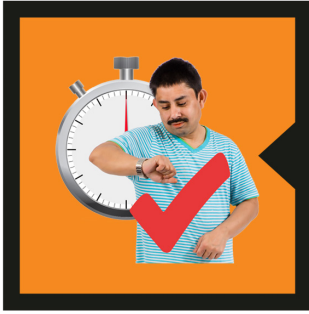
All 999 calls are given a colour, red, amber or green, like traffic lights.



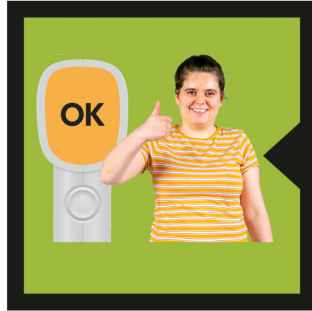
The colours help the ambulance service know how serious your problem is. And how quickly they need to send help.



**Red calls:** This is when someone is very ill and they might die if they do not get help straight away.



**Amber calls:** This is for problems that are serious but the person will not die if they do not get help straight away.



**Green calls:** This is when the problem is not serious.



If you phone 999, you may need an ambulance.

If an ambulance comes to you, the ambulance staff must check 7 important things:

- Temperature
- Blood pressure
- Oxygen levels
- Pulse
- Breathing
- Blood sugar
- Pain score



# What to do if you need to go into hospital



If you or someone you care for needs to go into hospital:

- for a planned appointment or treatment,
- or in an emergency,



contact the **Acute Learning Disability Liaison Nurse Service**.



Contact them as soon as you can. The sooner you contact them the better.



They will get information about you and your needs. And plan the best support for you.





Contact us if you need to know how to get in touch with the **Acute Learning Disability Liaison Nurse** for your hospital:

**E-mail:** [info@paulriddfoundation.org](mailto:info@paulriddfoundation.org)

**Phone:** 01639 820026

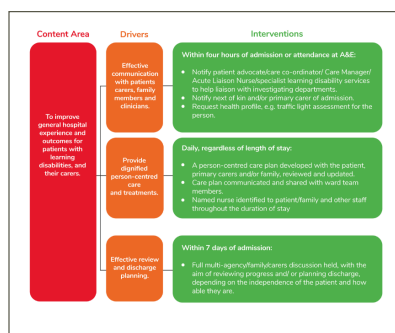
**Website:** [paulriddfoundation.org/resources-for-patients-families-carers](http://paulriddfoundation.org/resources-for-patients-families-carers)



When you get to hospital give your **Health Profile** to your healthcare staff.



This will help them make any **reasonable adjustments** you may need.



If you can, take a copy of the **Driver Diagram of the Care Bundle**. You can download this from our website here: [paulriddfoundation.org/resources-for-patients-families-carers](http://paulriddfoundation.org/resources-for-patients-families-carers)





You can use the **Driver Diagram of the Care Bundle** to make sure every step is followed properly. This is explained further on **page 25**.



When you are in hospital, ask if there is a **Learning Disability Champion** on the ward.



It is their job to make sure you have a good experience in hospital. And they will make sure all your healthcare staff know you may need a little extra help.

# Acute Learning Disability Liaison Referral Form



If you or someone you care for needs to go into hospital for a planned appointment, fill in the **Acute Learning Disability Liaison Referral Form**.



Once you have filled it in, send it to the **Acute Learning Disability Liaison Nurse** in your hospital as soon as possible.



This helps them to organise any extra support you may need whilst in hospital.



To get an **Acute Learning Disability Liaison Referral Form** contact us or your **Acute Learning Disability Liaison Nurse**:

E-mail: [info@paulriddfoundation.org](mailto:info@paulriddfoundation.org)

Phone: 01639 820026

Website: [paulriddfoundation.org/resources-for-patients-families-carers](http://paulriddfoundation.org/resources-for-patients-families-carers)



# Driver Diagram of Care Bundle



The **Driver Diagram of the Care Bundle** sets out 7 steps that must be followed when a person with a learning disability goes into hospital. They are explained below.

**Steps 1 to 3 must happen within 4 hours of being in hospital:**



1. Make sure everyone knows that there is a patient with a learning disability in hospital. For example, the care coordinator, care manager, Acute Liaison Nurse, and any other specialist learning disability services.



2. Make sure the patients' family or main carer knows they are in hospital.



3. Ask for the patients' **Health Profile**.

## Steps 4 to 6 should happen everyday:



4. Write a person-centred care plan with the patient, family or carers. This should be checked and updated as needed.



5. Share the care plan with ward staff.



6. Make sure the patient, family and staff know the **named nurse** that is looking after the person.

## Step 7 should happen within 7 days of being in hospital:



7. Hold a meeting with health and social care staff, family and carers to check how treatment is going. And to talk about sending the patient home when possible.

# Going home from hospital



When you are ready to go home, make sure there is a **discharge meeting**. This is a meeting where your family, carers, health and social care staff can talk about the safest and best way to get you back home.



Please tell us your story about what it was like for you in hospital. We want to celebrate the good things that are happening. And make sure we can improve things that are not going well.

## Thank you



We would like to thank Mencap Cymru for funding this information leaflet. Thank you also to The Austin Bailey Foundation for awarding us a grant.

And thank you to Dr Dawn Cavanagh for all her advice and support in creating this information leaflet. Thank you also to all of our supporters.

# How to contact us

If you need any further help and support, please contact The Paul Ridd Foundation or Mencap Cymru:

## Paul Ridd Foundation



**Website:** [paulriddfoundation.org](http://paulriddfoundation.org)

**Email:** [info@paulriddfoundation.org](mailto:info@paulriddfoundation.org)

**Phone:** 01639 820026

**Twitter:** [@Paulriddfound](https://twitter.com/Paulriddfound)

**Facebook:** [@thepaulriddfoundation](https://www.facebook.com/thepaulriddfoundation)

## Mencap Cymru



**Website:** [wales.mencap.org.uk](http://wales.mencap.org.uk)

**Email:** [information.wales@mencap.org.uk](mailto:information.wales@mencap.org.uk)

**Phone:** 0808 8000 300

**Twitter:** @MencapCymru

**Facebook:** [@MencapCymru](https://www.facebook.com/MencapCymru)

**Wales Learning Disability Helpline (Monday to Friday and Bank Holidays): 0808 8000 300**

# Useful numbers

## Community Learning Disability Teams

### Swansea Bay & Cwm Taf Health Boards

Bridgend CLDT - 01656 815353

RCT North CLDT - 01685 351279

RCT South CLDT - 01443 220418

Swansea CLDT - 01792 614100

Neath Port Talbot CLDT - 01639 682869

### Betsi Cadwaladr

Conwy CLDT - 01492 575374

Denbighshire CLDT - 01824 712750

Flintshire CLDT - 01352 701081

Gwynedd CLDT - 01341 424424

Wrexham CLDT - 01978 298484

Anglesey CLDT - 01248 751830



### **Cardiff and Vale Health Board**

Cardiff CLDT - 02920 674040

Vale of Glamorgan CLDT - 07821 808545

Out of hours - 02920 788570

### **Aneurin Bevan Health Board**

Blaenau Gwent CLDT - 01495 354666

Caerphilly CLDT - 01495 235532

Monmouthshire CLDT- 01873 735213

Newport CLDT - 01633 238956

Torfaen CLDT - 01633 624101

### **Hywel Dda Health Board**

Pembrokeshire CLDT - 01437 772819

Carmarthen CLDT - 01267 244388

Llanelli CLDT- 01554 744264

Ceredigion CLDT - 01545 572735

### **Powys Health Board**

Powys CLDT - 01874 712644

# Hard words

## Reasonable adjustments

Reasonable adjustments are changes that places and services can make to make sure everyone is able to use them. For example putting ramps in buildings for wheelchair users. Or giving information in easy read.