

# Contact Us

If you would like further information about our work  
please look at our website or email us:



"Supporting people with a Learning  
Disability to access equal healthcare."

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## Learning Disability Champions Information Booklet



## Paul Ridd Foundation

"Supporting people with a Learning Disability to access  
equal healthcare."



Bwrdd Iechyd Prifysgol:  
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Bae Abertawe | Swansea Bay University Health Board  
Betsi Cadwaladr | University Health Board  
Caerdydd a'r Fro | Cardiff and Vale University Health Board  
Cwm Taf | University Health Board  
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# About Us



The **Paul Ridd Foundation**, Registered Charity No: 1171739, has been created to support adults with a learning disability and their families and carers when needing healthcare. We want to make a difference for people with a learning disability by raising general awareness of the issues they face.

## Our Work

To promote awareness of the Pathway Care Bundle and our Logo for Adults with a Learning Disability requiring Hospital Care through:

- Sharing information with families and carers; awareness training with student nurses and medical staff at secondary care level.
- Providing every ward and department in every hospital in Wales with LD logo packs and Champion packs for patients with learning disabilities.
- Meeting with all Health Boards, Welsh Government, Mencap and various LD support groups to share our story and work towards a common approach to the healthcare of adults with a Learning Disability.
- Developing our website to provide online education and training, information for families, support and guidance.

# About learning disability

A learning disability is a reduced intellectual ability and difficulty with everyday activities – for example, household tasks, socialising or managing money – which affects someone for their whole life.

People with a learning disability tend to take longer to learn and may need support to develop new skills, understand complex information and interact with other people.

The level of support someone needs depends on individual factors, including the severity of their learning disability. For example someone with a mild learning disability may only need support with things like household bills or finding meaningful activities. Others with a severe or profound learning disability may need fulltime care and support with every aspect of their life – they may also have physical impairments.

Someone with a learning disability may need more time to think about what you are telling them. They also have limited communication skills, so won't be able to describe problems as well as other patients.

**“See the person not the disability.”**



# Who we've Helped

**Since Paul's death in 2009** we are passionate that other families should not have to suffer as we have suffered. We have sat on numerous panels and groups and shared our story across Wales, in Welsh Assembly Government and in Parliament to increase awareness of the issues faced by patients with LD.

We have seen the expansion of the Acute Liaison Nursing Service across Wales; the agreement of Welsh Government to implement mandatory learning disability awareness training throughout healthcare; the adoption of our logo by all Welsh Health Boards as a gentle reminder that the patient will need special care. We continue to campaign to see a common approach throughout all Wales and would like to see an increase in the uptake of the Annual Health check, and a common flagging system.

Thanks to funds raised by supporters we have been able to provide LD Logo Packs and Champion Packs for in every hospital in Wales.



# Paul's Story

*"We as a family have paid the ultimate price for the lack of training, ignorance and complacency"*



Paul Ridd was the eldest son of John & Andrea and brother to Jonathan & Jayne. He had severe learning disabilities and died in Morriston Hospital in 2009. The Public Services Ombudsman report into the circumstances leading to Paul's death said that neglect, lack of training and ignorance were contributory factors leading to Paul's death.

**The Care Bundle for Adults with a Learning Disability** and the **Paul Ridd Foundation** has been developed as a legacy to Paul.

**"See the person not the disability."**

# What does it mean to be a Learning Disability Champion?



The role of the Learning Disability Champion is an **important** one. Your support can really help the patient with learning disabilities, his carer and family to have the level of care they deserve.

Lack of awareness and understanding often means people with a learning disability are among the most excluded and disadvantaged people in society.

Your role is to work with the staff around you on your ward and with the hospital LD liaison nurse to provide reasonable adjustments so that the patient can access the care they need.

Use the Health Passport (Traffic Light Assessment) the patient will have brought in with them to help you understand their individual needs. If this hasn't been brought in there will be one available in the Care Bundle to complete with the patient/carer (see centre of booklet)  
Look for **reasonable adjustments** that can be made. Talk to your LD Liaison nurse about these.

**“See the person not the disability.”**

# Learning Disability and HealthCare



In recent years Mencap have highlighted a number of examples across the UK where people with a learning disability, despite having increased health needs, have received poorer healthcare. In the worst cases, it's been shown that some people have died, but many would have

had a better chance of surviving had more attention been paid to their needs as a person with a LD.



**Diagnostic overshadowing** can happen when preconceptions around someone's learning disability means that genuine health problems aren't spotted eg not noticing that someone has had a stroke because it is assumed they can't speak.

Many good initiatives have been introduced in Wales to improve the outcomes for people with a learning disability in the NHS, such as free Annual Health checks, Health Passports and Learning Disability Liaison nurses and Champions and learning disability awareness sessions in hospitals.

**“See the person not the disability.”** 8.



# The Care Bundle Resource File

Care Bundle Resource File  
for Adults with a Learning  
Disability

Requiring Hospital Care  
within Cardiff & Vale  
University Health Board

make it better fund  
make it better fund  
make it better fund  
make it better fund

The Care Bundle Resource File for Adults with a Learning Disability Requiring Hospital Care has been designed to help hospital staff ensure that people with a learning disability will receive a fair and equitable service when they visit hospitals. It is to be used whenever someone with a learning disability is admitted to a ward or visits a department in order that they

receive the care and treatment they deserve. **Every ward and department** should have a copy of the Care Bundle. If you cannot find a copy on your ward please contact your learning disability liaison nurse or contact us.

As a **LD Champion** it is important for you and all the staff on your ward to be familiar with the contents of the Care Bundle.

Our hope is that using the Pathway and Care Bundle will help ensure that what happened to Paul does not happen to anyone else with learning disabilities.

**“See the person not the disability.”**

## 10 things for Learning Disability Champions to share with staff on their ward

1. Give people **more time** to process information and respond to your questions.
2. Keep **questions open**, and rephrase what you've said if it looks like you haven't been understood.
3. **Don't use jargon** and explain conditions and procedures clearly.
4. **Talk to the person first.** Don't always go straight to the family or carer.
5. Involve parents and carers and **listen** to them when they have concerns. They are experts.
6. Read the person's **Health Passport** if they have one. In some areas these are called traffic lights. For further information see centre page of this booklet.
7. Think about the **Mental Capacity Act**. Consult the local lead on mental capacity if you aren't sure of anything.
8. If someone finds it hard to explain their symptoms or has limited speech, try using **models or diagrams** which they can refer to.
9. Attend regular **LD Champion training** and share with your colleagues.
10. If you need support, information or are concerned about a patient call your LD liaison nurse.





# Learning Disability Health Profile



All adults with learning disability should carry a completed Health Profile. Ask the patient for it, but if they do not have one please take time to complete this with the patient, carer and family members. .

**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: \_\_\_\_\_

A photo of me can be put here

**About My Health**

My health needs (medical History):

Things I am allergic to:

Tablets or medicine that I take:

The support I need to take my tablets or medicine:

How I will show you or tell you I am in pain or unwell:

The Health Profile is a grab sheet that should accompany a person with a learning disability into hospital whether the admission is an emergency admission or a planned admission.

The primary purpose of the form is to provide hospital staff with vital information about the patient's health and how they need you to support them.



It should be hung at the bottom of the patients bed and communicated on a daily basis to all ward staff.

For more information on the Health Profile please read section 3 of the Care Bundle.

**How I need you to support me (Including any reasonable adjustments I may need)**

How I need you to support me:

**How I need you to support me continued**

How we can best communicate:

Other important things I would like you to know about me:

Name of person completing this form:

## Reasonable Adjustments

Patients with a learning disability may need additional and alternative methods of support established with the patient and/or their families/carer in order to achieve a positive outcome.

As a Learning Disability Champion make sure you are aware of the patient's patient-centred care plan and the reasonable adjustments that can be made. Speak to your LD Liaison nurse if you need more advice.