

Access to healthcare information pack

For people with learning disabilities,
their families & carers



About this pack

This information pack has been produced by the Paul Ridd Foundation and Mencap Cymru to help people with a learning disability and their families and carers to access healthcare safely and equally.

The information in this pack will help to empower you through knowledge. It will help you to know and understand what rights you have and what support is already in place to assist you.

You will be able to find all the tools and information you need to receive equal healthcare.

Please get in touch with us if you need any further help or advice. Contact details can be found at the end of this pack.



The Paul Ridd Foundation



Find out more and read Paul's story at paulriddfoundation.org

The Paul Ridd Foundation was set up to support people with a learning disability, their families and carers. We want people with a learning disability to be valued in society and receive a fair and equitable service when receiving healthcare.

We want nurses, carers and people with a learning disability and their families and carers to be familiar with the Care Bundle, health profile and logo.

Our hope is that by using the health profile, receiving learning disability awareness training and ensuring the Care Bundle is adhered to that what happened to Paul does not happen to anyone else with a learning disability.

Ultimately we want to EMPOWER people with knowledge and training to make a difference to the healthcare of people with a learning disability.



The Paul Ridd Foundation



Our Key Aims

- Acute & Primary Care Liaison Nurse Service in every health board
- Quality Annual Health Check for all
- Learning Disability Champions on every ward in every hospital
- IT Flagging System
- Care Bundle Resource File and Logo Packs on each ward
- Mandatory Awareness Training for ALL NHS staff.



Mencap Cymru

Mencap Cymru is a provider of direct support services for people with a learning disability. They are also a campaigning and influencing organisation that wants Wales to be the best place to live for people with a learning disability. We at the Paul Ridd Foundation are privileged to work alongside them.

Everything Mencap Cymru does is about making sure people with a learning disability are valued equally, listened to and included.

The Wales Learning Disability Helpline, which is funded by the Welsh Government, is available Monday – Friday and is available for everyone in Wales whether you are a person with a learning disability, a family member or a friend.

They can give you advice, help you to access services, tell you your rights, and support you to challenge decisions.



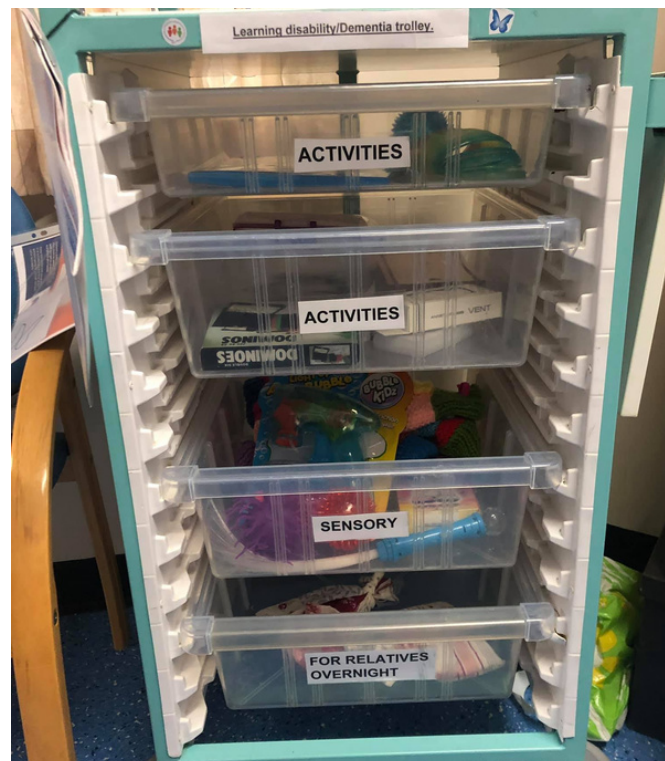
Find out more at:
wales.mencap.org.uk



Reasonable adjustments

Under the Equality Act 2010, people with a learning disability can expect reasonable adjustments to be made, to make their visit to the GP or hospital a more positive experience.

They are an “anticipatory duty” meaning that healthcare organisations have to consider the reasonable adjustments required in advance of the person turning up, so they must plan ahead.



Examples:

- An appointment at a quieter time, or a slightly longer appointment
- A quiet room to wait in A&E or in outpatients
- Easy read appointment letters
- Medical staff using simpler language
- Several procedures carried out under one anaesthetic
- Inviting the patient to a pre-admission visit to reduce anxiety

Annual Health Check



This is a health check that is carried out once a year for anyone with a learning disability over the age of 18, although this is being reviewed for it to change to 14. You do not have to be unwell to receive it.

In order to receive one, you **MUST** first check that you are on your GP's learning disability register, or request to be added to it.

If this is not possible, please contact us or your local community learning disability nursing team.

The health check is a physical examination, and a medical and medicine review. Any health issues arising should be summarised in a Health Action Plan, with simple, specific actions to improve your health.

A review date should be set for each task and this action plan should be shared with, and given to you at the end of the Annual Health Check.

It should also include annual check up reminders.

It's also a great way for you and your doctor to get to know one another!



What to expect

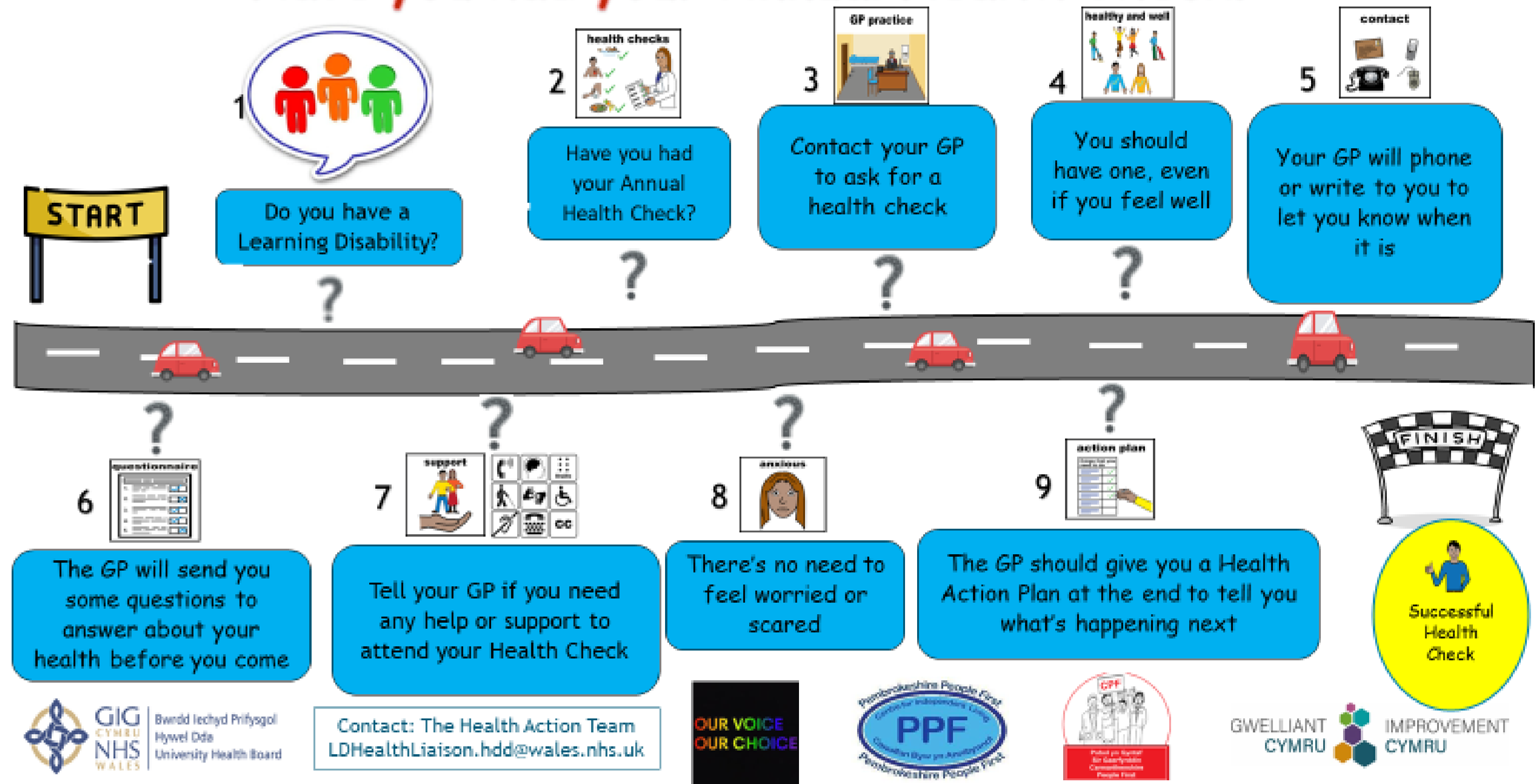
During your Annual Health Check, a doctor or nurse will:

- Check your blood pressure and listen to your heart.
- Ask about what you eat, if you exercise, and about your medication.
- Check your hearing and vision.
- Take a blood and/or a urine test.
- Talk to you about how you are feeling and if you have any worries.
- They may also ask for further tests or examinations.

The annual health check is a great way to stay healthy as your general health will be monitored regularly.

Always take someone with you if you feel more comfortable. Take your time and ask as many questions as you want.

Have you had your Annual Health Check?



Thank you so much to the health check champions of Hywel Dda UHB who developed this amazing resource!

Once For Wales Health Profile

GWEILLIANT CYMRU IMPROVEMENT CYMRU GIG CYMRU NHS WALES

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

Professionals

In Wales, the Once for Wales Health Profile contains information about a person's health, their communication style, their preferred care and support needs. It will help NHS staff make any reasonable adjustments to ensure good healthcare for people with a learning disability. It also contains guidelines about the need to record these adjustments.

Things to remember:

- Take it to every medical appointment, both emergency and planned.
- Keep it up to date, as it is a “living document” and any changes to anything relevant should be made.
- Don't forget to ask if help is needed to fill it in.
- Go to paulriddfoundation.org, under “Resources” to print off a copy, and to see guidelines on how to complete it.



Calling NHS 111 Wales

NHS 111 *Wales*

GIG 111 *Cymru*

- NHS 111 Wales is a **free** telephone service that is available 24 hours a day, every day.
- There is also a website where you can get lots of Easy Read information: 111.wales.nhs.uk.

You can use this service:

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





GIG
CYMRU
NHS
WALES

Ymddiriedolaeth GIG
Gwasanaethau Ambiwylans Cymru
Welsh Ambulance Services
NHS Trust

Calling 999

If you phone 999 for an ambulance, the ambulance service asks 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 to send help.



Red calls

These are life threatening emergencies. Life threatening means when someone is very ill and they might die if they do not get help straight away.

Amber calls

These are if the problem is serious but it is not life threatening.

Green calls

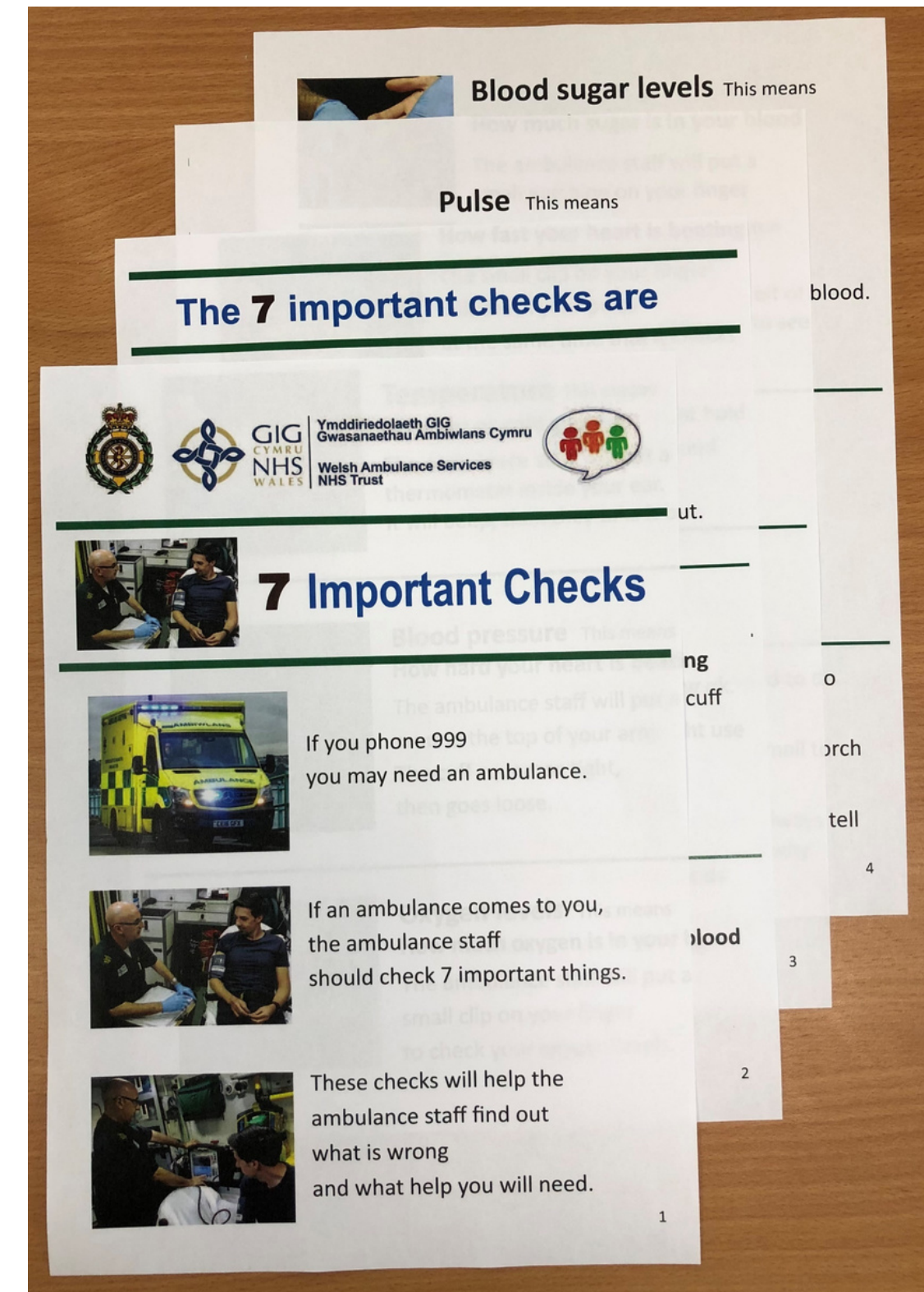
These are not life threatening and are not serious.

What to expect

If you phone 999 you may need an ambulance.

If an ambulance comes to you, the ambulance staff should check 7 important things about you, these are:

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



Email PECI.team@wales.nhs.uk if you would like a copy of this leaflet.

Going into hospital-planned visit

It is so important to make contact with the liaison nurse service before you go into hospital, so they have as much information about you as possible.

This is because the earlier they are aware of you or someone you care for who has a learning disability, the better the planning and support they can put in place.

You will also be able to discuss any specific needs with them, such as access to facilities or whether you will need a reclining chair if family is staying.

See our website for full list of contact numbers for the liaison nurse for your hospital, or get in touch with us.

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

It is their job to help make your stay in hospital a positive one, and to ensure that all healthcare workers are aware that you may need a little extra help.



Acute Learning Disability Liaison Referral Form

The form is titled "ACUTE LEARNING DISABILITY LIAISON REFERRAL". It includes sections for patient information (Forename, Surname, DOB, Home Address, Home Tel No), referral details (Date of Referral, Time of referral, Name of referrer, Consultant, Reason for admission), consent (Is the patient aware of this referral?, Is the relative aware of the referral?, Referral completed in the patient's best interest?), and clinical details (Reason for Referral, Next of Kin, GP, Telephone number, Known to Community LD Team, Care Package, Care Provider, Hours of Support, Advocate, Postural Management Plan, Behaviour Management Plan, Other). It also has a section for additional support services (Consultant Psychiatrist, Community Nurse, Speech and Language Therapist, Occupational Therapist, Physiotherapist, Psychologist, Dentist, Specialist Behavioural team) and a section for Type of Residence (Supported living, Family Home, Own Home, Residential home, Nursing home).

Before a hospital visit

If you, or someone you care for, needs to go to hospital for a planned outpatient appointment or for treatment, fill in this form and send it to the liaison nurses for your hospital as soon as possible.

This way they can organise and put in place any additional support for you.

Call the Paul Ridd Foundation or the liaison nurses to receive a copy.



Going into hospital-unplanned visit

If you, or someone you care for is taken ill and rushed into hospital, it is essential that the learning disability liaison nurse is contacted within 4 hours.

It is also vital that your health profile is given to any healthcare staff immediately so that any reasonable adjustments can be made for you.

See our website for full list of contact numbers for the liaison nurse for your hospital, or get in touch with us.



Acute Learning Disability Liaison Nurse Service

When Paul died, there were two acute learning disability liaison nurses across Wales.

「We are delighted that there are now
19 nurses across all 7 health boards.」

They are there to support you within the hospital setting and to help make your hospital visit a good experience.

Please let us know what your experience is like, we want to hear your stories. We also want this service to expand, so all feedback, both positive and negative will help it to grow.

Contact us if you need to know how to get in touch with the liaison nurse for your local hospital.



Learning Disability Champions

The Paul Ridd Foundation has trained over 2,000 learning disability champions within hospitals in Wales, and more champions are being trained every month!



Learning Disability Champions are there to support you and your family when you are in hospital by making any reasonable adjustments you may need.



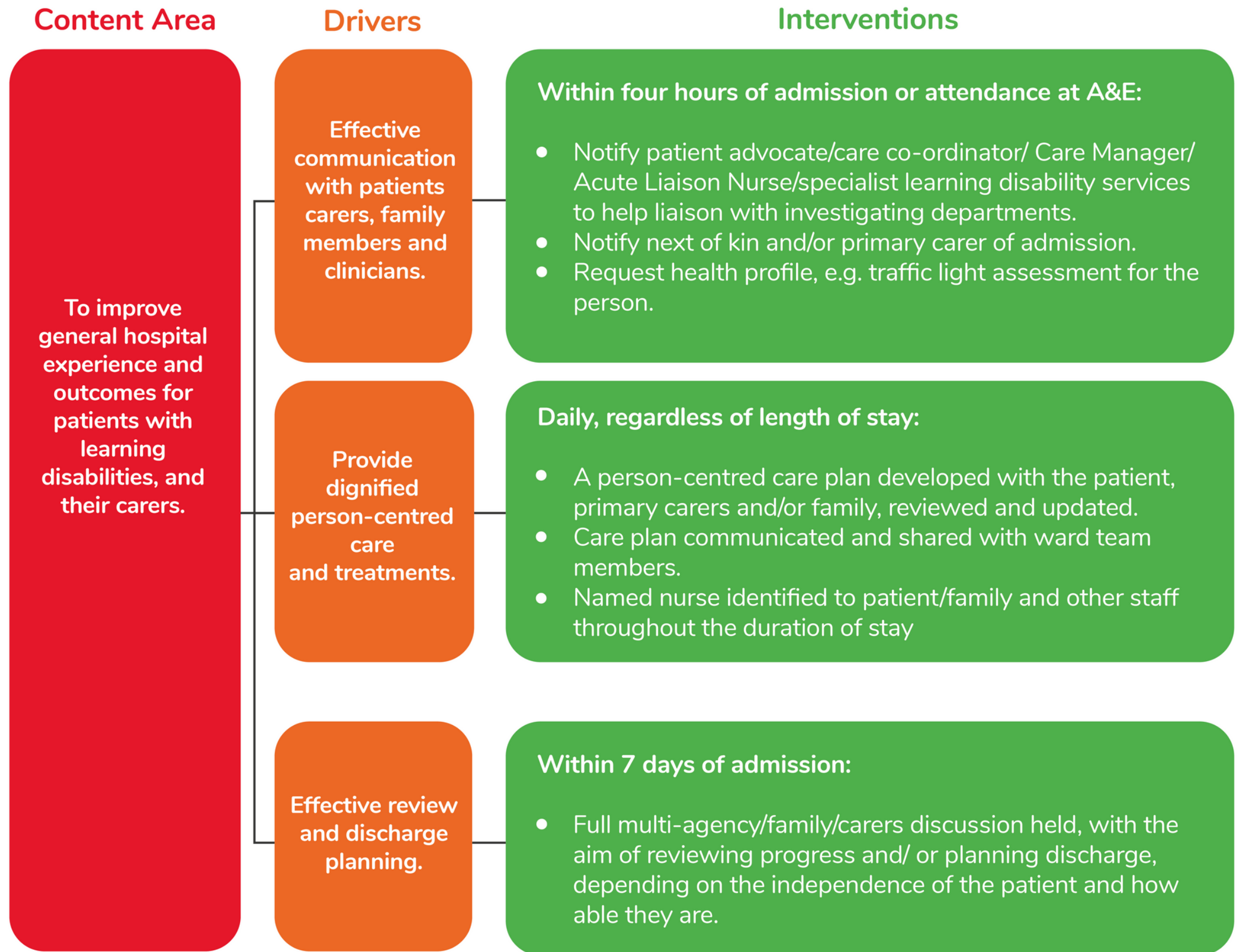
They will also remind other healthcare staff that you might need some extra support.

Check the noticeboard on your ward for details of who is the ward champion. If there is no information please let us know.

In hospital

The seven steps in green **MUST** be followed when a patient with a learning disability goes into hospital.

Go to paulriddfoundation.org, under “Resources for parents & carers” to print off a copy for when you go into hospital.



Things to remember

Make sure you have an up-to-date copy of your health profile with you and a copy of the driver diagram so you can ensure that every step is followed correctly.

These can be downloaded from our website www.paulriddfoundation.org



Going home

When you are ready to go home, make sure that there is an effective meeting with all parties included, such as families, carers and healthcare staff so that there can be the safest discharge possible for you.

Don't forget to let us know how your stay in hospital has gone, as we want to hear your stories! This way we can celebrate the good and campaign for change when things don't go well.



Thank you



We would like to thank Mencap Cymru for their generous support in funding the production of these information packs, as well as The Austin Bailey Foundation for awarding us a grant.

Thank you to Dr Dawn Cavanagh for that initial chat many months ago when the need for these packs became apparent.

As ever we would like to thank our supporters who keep us going when we hear yet another story of lack of care or neglect and feel like giving up...

But we will continue to fight for equality of healthcare for people with a learning disability to continue Paul's legacy.

Contacts

Paul Ridd Foundation

 paulriddfoundation.org

 info@paulriddfoundation.org

 01639 820026

 @Paulriddfound

 @thepaulriddfoundation

Mencap Cymru

 wales.mencap.org.uk/

 information.wales@mencap.org.uk

 0808 8000 300

 @MencapCymru

 @MencapCymru

**Wales Learning
Disability Helpline:** **0808 8000 300**
Monday-Friday

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

Useful numbers

Community Learning Disability Teams

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

Useful numbers

Community Learning Disability Teams

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

Please use the following pages for making note of any useful numbers or contacts:

Notes: