



**RARE**  
resources  
W A L E S



**3 Defnyddio'r GIG yng  
Nghymru**  
**3 Using the NHS in Wales**

Mae Rare Resources yn gasgliad o ganllawiau gwybodaeth i deuluoedd sydd wedi cael diagnosis o gyflyr genetig neu brin yn ddiweddar, sydd ar y daith at ddiagnosis, neu sydd wedi cael gwybod bod cyflyr eu plentyn mor brin fel na fyddant yn cael diagnosis efallai.

Datblygwyd y canllawiau Rare Resources mewn cydweithrediad rhwng Genetic Alliance UK a theuluoedd yng Nghymru. Mae'r canllawiau'n rhoi dolenni at ffynonellau gwybodaeth a chymorth dibynadwy, ac yn cynnwys 'awgrymiadau da' gan deuluoedd eraill.

Mae Rare Resources yn cynnwys y canllawiau canlynol:

1. Eglurhad o gyflyrau genetig, prin a heb ddiagnosis
2. Y daith at ddiagnosis
3. Defnyddio'r GIG yng Nghymru
4. Cymorth a gwybodaeth i rieni a gofalwyr
5. Cymorth a gwybodaeth i'ch plentyn
6. Cyfeiriadur gwybodaeth sy'n rhoi manylion y gwasanaethau cymorth sydd ar gael yng Nghymru

Gellir lawrlwytho'r canllawiau Rare Resources o [bit.ly/rarerесourceswales](http://bit.ly/rarerесourceswales)

Rare Resources is a collection of information guides for families who have recently received a diagnosis of a genetic or rare condition, are on the journey to a diagnosis, or have been told their child's condition is so rare they might not get a diagnosis.

The Rare Resources guides have been developed in collaboration between Genetic Alliance UK and families in Wales. The guides provide links to reliable sources of information and support, and contain 'top tips' from other families.

Rare Resources contains the following guides:

1. Genetic, rare and undiagnosed conditions explained
2. The journey to diagnosis
3. Using the NHS in Wales
4. Support and information for parents and carers
5. Support and information for your child
6. Information directory detailing support services available in Wales

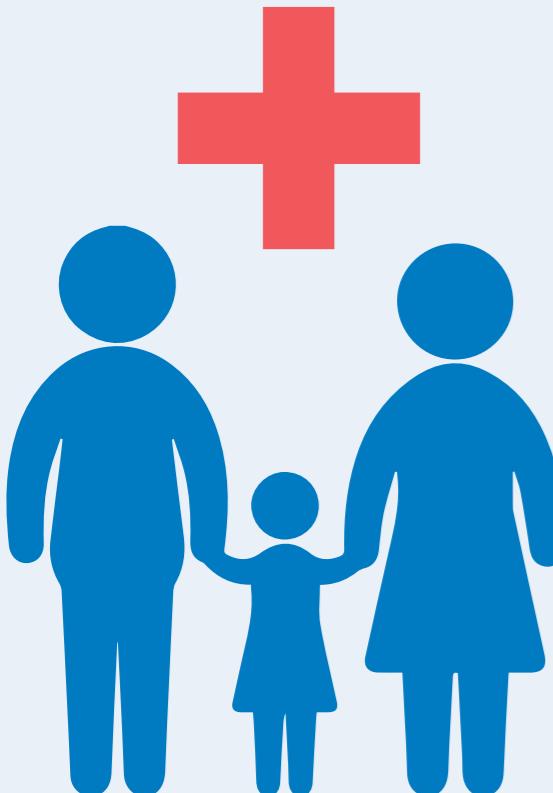
The Rare Resources guides can be downloaded from [bit.ly/rarerесourceswales](http://bit.ly/rarerесourceswales)

- 3.1 [Defnyddio'r Gwasanaeth Iechyd Gwladol \(GIG\) yng Nghymru](#)**
- 3.2 [Beth mae'r GIG yng Nghymru yn ei ddarparu i blant sydd â chyflyrau genetig, prin neu heb ddiagnosis?](#)**
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# 3.1 Defnyddio'r Gwasanaeth lechyd Gwladol (GIG) yng Nghymru

## 3.1 Using the NHS in Wales



Mae llawer o deuluoedd sydd â phlentyn â chyflwr genetig, prin neu heb ddiagnosis yn defnyddio gwasanaethau'r GIG yng Nghymru yn fwy rheolaidd.

For many families, having a child with a genetic, rare or undiagnosed condition means using NHS services in Wales with greater regularity.

Gall hyn fod yn brofiad newydd i lawer o deuluoedd.

'Rydw i'n cofio'r holl jargon yr oedd y doctoriaid yn yr ysbty yn ei ddefnyddio – roedd hi fel dysgu iaith newydd.'

Aelod gweithdy

Yn yr adran hon, cewch wybodaeth am y GIG yng Nghymru a sut i wneud y gorau o'ch apwyntiadau. GIG Cymru yw'r Gwasanaeth lechyd Gwladol a gyllidir yn gyhoeddus sy'n darparu gofal iechyd i gleifion yng Nghymru. GIG Cymru sy'n darparu'r rhan fwyaf o'r gwasanaethau iechyd y bydd eich plentyn yn eu cael a'r GIG sy'n gyfrifol am wasanaethau meddygon teulu, ysbtyai a gwasanaethau arbenigol.

'Cyn i mi gael fy merch, prin fu'n rhaid i ni ddefnyddio'r GIG am unrhyw reswm arall ar wahân i ychydig o apwyntiadau efo'r meddyg teulu. Bellach, rydw i'n 'teimlo 'mod i'n 'nabod pob wyneb a phob cornel yn ein ysbty!'

Aelod gweithdy

Mae GIG Cymru wedi'i rannu'n saith Bwrdd lechyd daearyddol sy'n gyfrifol am ddarparu'r GIG yn eu hardal leol.

Mae'r rhan fwyaf o driniaeth y GIG am ddim, gan gynnwys costau presripsiwn, ond mae rhai pethau y gellir codi tâl amdanyst (h.y. triniaethau deintyddol).

Ar wefan GIG Cymru, cewch fanylion am y costau hyn a chyngor ar sut i gael cymorth ariannol os bydd angen hyn arnoch chi:

<https://gov.wales/help-with-health-costs>

For many families, this might be a new experience.

'I remember all the jargon the doctors in the hospital used – it was like learning a new language.'

Workshop participant

This section provides information on the NHS in Wales and how to make the most of your appointments. NHS Wales is the publicly funded healthcare system responsible for the care of patients in Wales. The NHS in Wales provides most of the health services your child will access and is responsible for GP, hospital and specialist services.

'Before I had my daughter, we hadn't really had to use the NHS for anything other than a few GP appointments. I now feel like I know every person and every corner of our hospital!'

Workshop participant

NHS Wales is divided into seven geographical Health Boards which have the responsibility for running the NHS in their local area.

Most NHS treatment is free, including all prescription costs, but there are some things for which there may be charges (e.g. dental treatments).

NHS Wales provides details on charges and advice on how to obtain financial support, if you need it, on their website:

<https://gov.wales/help-with-health-costs>

## 3.2 Beth mae'r GIG yng Nghymru yn ei ddarparu i blant sydd â chyflyrau genetig, prin neu heb ddiagnosis?

### 3.2 What does the NHS in Wales provide for children with genetic, rare or undiagnosed conditions?



Mae GIG Cymru yn gyfrifol am ddarparu gofal i blant sydd â chyflyrau genetig, prin neu heb ddiagnosis yng Nghymru.

NHS Wales is responsible for providing care for children with genetic, rare or undiagnosed conditions in Wales.

Mae hyn yn cynnwys apwyntiadau efo meddyg teulu, apwyntiadau efo clinigwyr arbenigol, ymweliadau â chanolfannau genetig rhanbarthol ac amrywiaeth eang o wasanaethau eraill.

Mae GIG Cymru hefyd yn comisiynu gwasanaethau arbenigol i gyflyrau prin (gan gynnwys gwasanaethau ar gyfer cyflyrau genetig a heb ddiagnosis).

Mae'r gwasanaethau sydd ar gael ar gyfer cyflyrau genetig, prin neu heb ddiagnosis yn amrywiol ac yn eang.

Ni fyddai'n bosibl rhestru'r holl wasanaethau yn yr Adnodd hwn ond nodir ble i gael mwy o wybodaeth amdanyst yn yr adran 'Mwy o wybodaeth' isod.

Mae Pwyllgor Gwasanaethau lechyd Arbenigol Cymru yn gyfrifol am gomisiynu, yn genedlaethol, gwasanaethau arbenigol iawn na ellir eu darparu yn lleol nac yn rhanbarthol.

Ar y cyfan, mae'r gwasanaethau hyn yn ymwneud â diagnosis ac/neu driniaeth ar gyfer cyflyrau prin.

Gyda'r amrywiaeth o gyflyrau prin a'r wybodaeth arbenigol sydd ei hangen i wneud diagnosis ohonyн а'u trin, nid yw hi wastad yn bosibl cael gwasanaeth i gyflwr prin yn agos at eich cartref.

Weithiau, nid oes modd dod o hyd i arbenigwr yng Nghymru a bydd rhaid i blentyn deithio i ran arall o'r DU i gael gofal arbenigol. Mae Pwyllgor Gwasanaethau lechyd Arbenigol Cymru yn gyfrifol am gomisiynu gwasanaethau arbenigol o lefydd eraill yn y DU a sicrhau bod cleifion Cymru yn gallu eu defnyddio nhw.

This includes GP appointments, appointments with specialist clinicians, visits to NHS regional genetic centres and a wide variety of other services.

NHS Wales also commissions specialist services for rare conditions (including services for genetic and undiagnosed conditions).

The services available for genetic, rare or undiagnosed conditions are varied and wide ranging.

It would not be possible to list all services in the Toolkit but you can find out where to access more information about them in the 'Further Information' section below.

The Welsh Health Specialised Services Committee (WHSSC) is responsible for the national commissioning for very specialist services which cannot be provided at a local or regional level.

These services are generally concerned with the diagnosis and/or treatment of rare conditions.

The diversity of rare conditions and the specialist knowledge required to diagnose and treat them means that it is not always possible to have a service for a rare condition available near to home.

Sometimes a specialist can't be found in Wales and a child will have to travel to another part of the UK to access specialist care. The WHSSC is responsible for the commissioning of specialist services from elsewhere in the UK and ensuring that Welsh patients are able to access them.

# 3.3 Sut i fynd at wasanaethau'r GIG i'ch plentyn

## 3.3 How to access NHS services for your child



### Top Tips From Parents

**Gofynnwch am enwau** – Peidiwch â bod ofn gofyn i bawb pwy ydi pwy a pham eu bod nhw'n rhoi gofal i'ch plentyn. Peidiwch â theimlo cywilydd os wnewch chi anghofio eich bod chi wedi cyfarfod â rhywun o'r blaen.

**Cadwch gofnod** – Mae'n gallu bod yn ddefnyddiol cadw cofnod o'r holl apwyntiadau rydych chi wedi'u cael, a pha feddygon neu weithiwr iechyd proffesiynol rydych chi wedi'u gweld.

**Gofynnwch am weld yr un person** – Os yn bosib, gofynnwch am gael gweld yr un meddyg teulu neu'r un gweithiwr iechyd proffesiynol pob tro. Fel hyn, byddwch yn meithrin perthynas efo nhw a byddan nhw yn dod i ddeall anghenion eich plentyn yn well gobeithio.

**Gofynnwch am help efo apwyntiadau** – Peidiwch â bod ofn gofyn am rywun i helpu cydlynu apwyntiadau neu ofal eich plentyn. Gallai nrys, gweithiwr proffesiynol arweiniol neu gorff trydydd sector wneud hyn.

**Gofynnwch am bwynt cyswllt** – Fel hyn gallwch gysylltu â rhywun rhwng apwyntiadau os bydd gennych chi unrhyw gwestiynau.

**Ask for names** – Don't be afraid to ask everyone you see who they are and why they are involved. Don't be embarrassed about forgetting if you've met someone before.

**Keep records** – It can be helpful to keep a record of all the appointments that you have had, and which doctors or health professionals you have seen.

**See the same person** – If possible, make a request to see the same GP or health professional each time. That way you can build a relationship with them and they will hopefully build a better understanding of your child's needs.

**Ask for help with appointments** – Don't be afraid to ask for someone to help coordinate your child's appointments or care. This might be facilitated by a nurse, lead professional or a third sector organisation.

**Ask for a point of contact** – This way you can get in touch with someone in between appointments if you have any questions.

Os ydych chi'n poeni am ddatblygiad neu iechyd eich plentyn, neu os ydych chi'n meddwl bod angen i'ch plentyn gael gwasanaeth penodol gan y GIG, yna mae'n syniad da trafod hyn efo eich meddyg teulu neu eich ymwelydd iechyd yn y lle cyntaf.

If you have concerns about your child's development or their health, or if you think your child needs to access a particular NHS service, it is a good idea to discuss this with your GP or your health visitor in the first instance.

Efallai y byddwch chi eisiau gwneud rhestr o'ch pryderon ac unrhyw symptomau neilltuol neu batrymau ymddygiad yr ydych chi wedi sylwi arnynt er mwyn i chi gael siarad amdanynt.

Gallwch hefyd wneud fideo neu dynnu lluniau ohonynt i fynd efo chi i'r apwyntiad.

Bydd eich meddyg teulu neu ymwelydd iechyd yn trafod eich pryderon efo chi. Mae'n debyg y byddant yn archwilio eich plentyn ac yn trafod opsiynau efo chi. Gall hyn olygu cael eich cyfeirio at wasanaethau eraill, fel paediatregydd, clinigydd arbenigol neu weithiwr iechyd proffesiynol arall fel ffisiotherapydd neu therapydd lleferydd.

Yn yr adran 'Pwy sy'n gwneud beth yn y GIG?' cewch rywfaint o wybodaeth gyffredinol am wasanaethau sydd ar gael a'r gwahanol glinigwyr arbenigol.

You may wish to make a list of your concerns and any particular symptoms or patterns of behaviour that you have noticed so you can talk them through.

You can also video them or take photos to take along to the appointment.

Your GP or health visitor will discuss your concerns with you. It is likely that they will also examine your child and discuss options with you. This may include referral to other services, such as a paediatrician, specialist clinician or another health professional such as a physiotherapist or speech therapist.

In the section 'Who does what in the NHS?' you will find some general information about services that are available and the range of specialist clinicians.



### Top Tips From Parents - Managing Appointments

**Get organised** – Keep a copy of all letters and test results together. Consider getting a ring binder and collect these letters together in date order. This will ensure you have the right important information together and help you keep track of your child's progress.

**Make appointments work for you** – If your child doesn't like attending a certain appointment or doesn't like a long wait, speak to the receptionist and explore other options to the waiting room. Is there a quiet room you could wait in? Could you wait outside with your child and be called in when the doctor is ready?

**Rhowch drefn ar bethau** – Cadwch gopi o'r holl lythyrau a'r canlyniadau profion efo'i gilydd. Meddyliwch am gael ffeil fawr a hel y llythyrau i gyd efo'i gilydd a'u trefnu yn ôl dyddiad. Fel hyn, bydd yr wybodaeth bwysig i gyd mewn un lle a gallwch chi gadw golwg ar gynnydd eich plentyn.

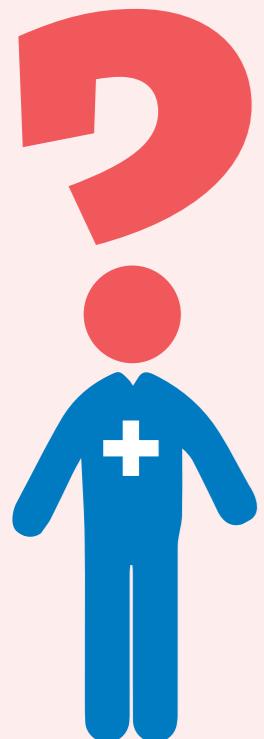
**Gwnewch i'r apwyntiadau weithio i chi** – Os nad yw eich plentyn yn hoffi mynd i ryw apwyntiad neilltuol neu ddim yn hoffi aros yn hir, siaradwch â'r derbynnydd ac edrych ar opsiynau eraill i'r ystafell aros. A oes ystafell dawel ble galleg chi aros? Allech chi aros tu allan efo'ch plentyn a chael eich galw i mewn pan fydd y meddyg yn barod?

## 3.4 Pwy sy'n gwneud beth yn y GIG?

Os oes gennych blentyn sydd â chyflwr genetig, prin neu heb ddiagnosis, efallai bydd rhaid gweld nifer o wahanol weithwyr gofal iechyd proffesiynol. Mae llawer o wahanol fathau o weithwyr gofal iechyd proffesiynol sy'n gweithio yn y GIG yng Nghymru.

## 3.4 Who does what in the NHS?

Having a child with a genetic, rare or undiagnosed condition might mean having to see a number of different healthcare professionals. There are many different types of healthcare professionals working within the NHS in Wales.



## Gweithiwr gofal iechyd proffesiynol

	Disgrifiad
Gweithiwr Proffesiynol Perthynol i lechyd	Term am weithiwr iechyd proffesiynol heb fod yn feddyg neu'n nyrs. Er enghraift, ffisiotherapyddion, therapyddion galwedigaethol a therapyddion iaith a lleferydd.
Nyrs Reolwr Glinigol	Nyrs sy'n gyfrifol am reoli ward neu uned.
Nyrs Glinigol Arbenigol	Nyrs sydd wedi cael hyfforddiant arbenigol i fod yn arbenigwr mewn un maes gofal iechyd.
Gweithiwr Cefnogol Clinigol (neu nyrs gynorthwyl)	Helpu nyrsys cofrestredig i ofalu am gleifion.
Ymgynghorydd	Uwch-feddyg sy'n ymarfer mewn un o'r arbenigeddau meddygol.
Nyrs ardal	Nyrs sy'n gofalu am gleifion yn y gymuned.
Meddyg Teulu	Meddyg yn y gymuned sy'n trin cleifion sydd â mân salwch neu salwch cronig ac yn cyfeirio'r rheiny sydd â chyflyrau difrifol i'r ysbyty.
Cwnselydd Genetig	Gweithiwr iechyd proffesiynol sydd wedi'i hyfforddi i roi cymorth, gwybodaeth a chyngor am gyflyrau genetig.
Nyrs Genetig	Nyrs gofrestredig sydd wedi cael addysg a hyfforddiant arbennig yn y maes geneteg.
Ymwelydd Iechyd	Nyrs gymwys a chofrestredig neu fydwraig sydd wedi dewis cael hyfforddiant a chymwysterau ychwanegol. Maent yn bennaf yn gweithio yn y gymuned efo plant o'u geni hyd at bum mlwydd oed a'u teuluoedd.
Bydwraig	Gweithiwr iechyd proffesiynol cymwys sy'n gofalu am ferched drwy gydol eu beichiogrydd, y genedigaeth, a'r cyfnod ôl-eni yn ogystal â gofalu am fabis newydd-anedig.
Gweithiwr Iechyd Meddwl Proffesiynol	Gweithiwr proffesiynol sy'n delio gydag ystod eang o broblemau iechyd meddwl a chorfforol gan gynnwys gorbryder, iselder, anawsterau dysgu a phroblemau yn ymwnud â pherthynas.
Therapydd Galwedigaethol	Gweithiwr Proffesiynol Perthynol i lechyd sy'n hybu iechyd a lles drwy ddefnyddio gweithgareddau penodol i helpu cleifion i wella neu hunan reoli cyflwr.
Paediatregydd	Ymarferydd meddygol sy'n arbenigo mewn iechyd corfforol, meddyliol a chymdeithasol plant o'u geni hyd at pan fyddant yn oedolion ifanc.
Fferyllydd	Gweithiwr iechyd proffesiynol sy'n arbenigo mewn meddyginaethau a'u defnydd. Maent yn cynghori staff meddygol a nyrsio ac yn rhoi gwybodaeth i gleifion.
Ffisiotherapydd	Helpu pobl sydd ag anaf, salwch neu anabledd drwy symud a gwneud ymarfer corff, therapi llaw, addysg a chyngor. Maent yn rhoi cyngor ar reoli poen.
Nyrs Practis	Nyrs sy'n gweithio yn y gymuned, mewn meddygfa meddyg teulu neu ganolfan iechyd leol fel arfer.
Therapydd laith a Lleferydd	Gweithiwr Proffesiynol Perthynol i lechyd sy'n rhoi sylw i broblemau efo iaith, lleferydd a chyfathrebu.

## Healthcare Professional

	Description
Allied Health Professional (AHP)	A term for a health professional that is not a doctor or nurse. For example, physiotherapists, occupational therapists and speech and language therapists.
Clinical Nurse Manager	A nurse responsible for the management of a ward or a unit.
Clinical Nurse Specialist	A nurse who has undertaken specialist training to become an expert in one area of healthcare.
Clinical Support Worker (or auxiliary nurse)	Assists registered nurses with patient care.
Consultant	A senior doctor who practises in one of the medical specialties.
District Nurse	A nurse that looks after patients in the community.
General Practitioner (GP)	A doctor based in the community who treats patients with minor or chronic illnesses and refers those with serious conditions to a hospital.
Genetic Counsellor	A health professional trained to provide support, information and advice about genetic conditions.
Genetic Nurse	A registered nurse with special education and training in genetics.
Health Visitor	A qualified and registered nurse or midwife who has chosen to gain additional training and qualifications. They mainly work in the community with children from birth to five years old and their families.
Midwife	A qualified health professional that cares for women throughout pregnancy, birth, and during the postnatal period, as well as caring for newborn babies.
Mental Health Professional	A professional that deals with a wide range of mental and physical health problems including anxiety, depression, learning difficulties and relationship issues.
Occupational Therapist (OT)	An AHP who promotes health and wellbeing through the use of particular activities as an aid to recuperation or self-management of a condition.
Paediatrician	A medical practitioner specialising in the physical, mental, and social health of children from birth to young adulthood.
Pharmacist	A health professional who is an expert in medicines and their use. They advise medical and nursing staff and provide information to patients.
Physiotherapist	Helps people affected by injury, illness or disability through movement and exercise, manual therapy, education and advice. They provide advice on pain management.
Practice Nurse	A nurse who works in the community, usually in a GP surgery or local health centre.
Speech and Language Therapist	An AHP who addresses speech, language and communication problems.

# 3.5 Beth i'w ddisgwyl mewn apwyntiadau meddygol

## 3.5 What to expect from medical appointments



I lawer o deuluoedd sydd â phlentyn â chyflwr genetig, prin neu heb ddiagnosis, mae rheoli llawer o wahanol gysylltiadau meddygol yn gallu bod yn brofiad emosiynol, dryslyd ac weithiau'n straen.

For many families who have a child with a genetic, rare or undiagnosed condition, managing lots of different medical interactions can be an emotional, confusing and sometimes stressful experience.

### Dyma rai o'r pethau allai fod yn eich wynebu:

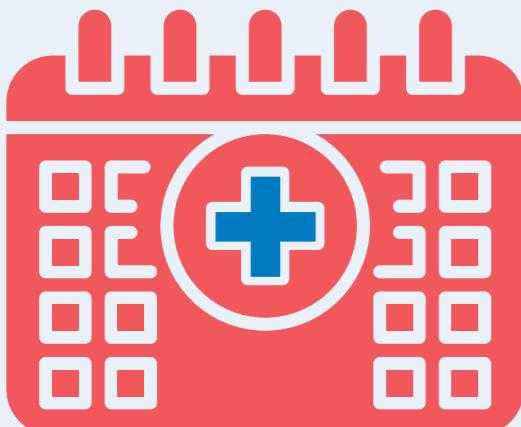
- Llawer o apwyntiadau i fynd iddynt
- Gorfod mynd i wahanol ysbtyai neu wasanaethau iechyd
- Gorfod treulio llawer o amser yn yr ysbty
- Gorfod cael llawer o weithwyr gofal iechyd proffesiynol yn gofalu am eich plentyn
- Gorfod ailadrodd symptomau ac anghenion eich plentyn i wahanol weithwyr gofal iechyd proffesiynol
- Gorfod 'dysgu'r iaith' y mae gweithwyr iechyd proffesiynol yn ei defnyddio a'i deall, a deall jargon meddygol
- Gorfod dysgu sut i ddarparu gofal iechyd i'ch plentyn
- Cael nyrsys, gofalwyr a therapyddion yn rhoi gofal yn eich cartref
- Efallai bydd angen i'ch plentyn gael ei gyfeirio at arbenigwr clinigol ac ymgynghorydd arbenigol. Er enghraifft, efallai caiff plentyn sydd â chyflwr prin sy'n effeithio ar ei system imiwnedd ei gyfeirio at yr adran imiwnoleg (arbenigwr clinigol) i weld imiwnolegydd ymgynghorol (arbenigwr mewn imiwnoleg).

### Some of the things you might experience include:

- Having lots of appointments to attend
- Having to visit different hospitals or health services
- Having to spend a lot of time in hospitals
- Having to have many different health care professionals involved in your child's care
- Having to repeat your child's symptoms and needs to different health professionals
- Having to 'learn the language' that health professionals use and understand medical jargon
- Having to learn how to provide healthcare for your child
- Having nurses, carers and therapists providing care in your home
- Your child may need to be referred to a clinical specialty and a specialist consultant. For example, a child with a rare condition affecting their immune system may be referred to immunology (the clinical specialty) to see a consultant immunologist (a specialist in immunology)

# 3.6 Rheoli apwyntiadau

## 3.6 Managing appointments



**Efallai bydd rhaid i deuluoedd plant sydd â chyflwr genetig, prin neu heb ddiagnosis fynd i lawer o apwyntiadau gofal iechyd gwahanol.**

**Families who have a child with a genetic, rare or undiagnosed condition may have to attend many different healthcare appointments.**

### Paratoi am eich apwyntiadau

Meddyliwch beth rydych chi eisiau ei drafod a pha gwestiynau rydych chi eisiau eu gofyn. Cyn i chi fynd, nodwch unrhyw gwestiynau yr ydych chi eisiau ateb iddynt a mynd â nhw efo chi fel nad ydych chi'n anghofio.

### Cadw cofnod

Cadwch gofnod o'r apwyntiadau sydd gennych, efo pwy oedden nhw a nodiadau byr ar yr hyn a drafodwyd. Gall hyn helpu wrth edrych yn ôl a thrafod ag eraill sydd hefyd yn rhoi gofal i'ch plentyn.

### Cofnodi cynnydd eich plentyn

Os bydd eich plentyn yn cael dyddiau da a gwael, gall fod yn fuddiol i chi nodi'r rhain a'r hyn oedd yn wahanol ar y dyddiau hyn. Os yn bosib, tynnwch lun neu fideo i ddangos i'ch meddyg.

Gallai hyn helpu eich gweithiwr gofal iechyd proffesiynol i ddeall cyflwr eich plentyn yn well, neu weld patrwm neu gliw allai arwain at ddiagnosis efallai.

### Trefnu apwyntiadau i'ch siwtio chi

Ceisiwch drefnu apwyntiadau ar amseroedd sy'n siwtio chi. Os cewch lythyr apwyntiad efo amser anghyfleus, peidiwch â bod ofn ffônio a gofyn am amser sy'n fwya addas.

### Gall apwyntiadau yn y bore weithiau leihau'r siawns o orfod aros yn hir

Mae oedi yn tueddu i fynd yn hirach wrth i'r diwrnod fynd yn ei flaen. Archwiliwch opsiynau ar gyfer ymgynghoriadau dros y ffôn neu drwy alwad fideo i lleihau'r angen i deithio.

### Egluro

Os yw eich plentyn yn ofnus am fynd i apwyntiad neilltuol neu am gael triniaeth neilltuol, meddyliwch sut allwch chi egluro beth sydd am ddigwydd o flaen llaw mewn ffordd a fydd yn ei gysuro.

Yn Ysbyty Arch Noa i Blant Cymru, mae tîm chwarae arbenigol yn gallu helpu eich plentyn i ddeall mwy am fod yn yr ysbyty a sut i ymdopi â gorbryder a theimladau tebyg.

### Prepare for your appointments

Have a think about what it is you want to discuss and what questions you want to ask. Write down any questions you want answered before you go and take them with you so you do not forget.

### Keep records

Keep records of the appointments you have, who they were with and short notes on what was discussed. This can be helpful to reflect upon and to discuss with others involved in your child's care.

### Record your child's progress

If your child has good days and bad days, it might be helpful to note these down and record what was different on these days. If possible, take a photo or a video to show your doctor.

This might help your healthcare professional better understand your child's condition or possibly spot a pattern or a clue that could lead to diagnosis.

### Arrange appointments to suit you

Try to arrange appointment times to suit you. If you receive an appointment letter with a time that is not convenient, don't be afraid to call and ask for a more suitable time.

### Appointments in the morning can sometimes reduce the chance of a long wait

Delays tend to get longer as the day goes on. Explore options for consultations by phone or by video call to reduce the need for travel.

### Explain

If your child is scared about attending a particular appointment or having a particular procedure, think about how you can explain what is going to happen beforehand in a way that will reassure them.

In Noah's Ark Children's Hospital for Wales a specialist play team can help your child understand more about being in hospital and to cope with anxieties and feelings associated with this.

## 3.7 Cadw cofnod

## 3.7 Keeping records

Gall fod dipyn o waith papur pan fo gennych blentyn sydd â chyflwr genetig, prin neu heb ddiagnosis. Efallai y cewch dipyn o lythyrau, canlyniadau profion a gwybodaeth o'r gwahanol apwyntiadau fydd gennych.

There can be a lot of paperwork involved when you have a child with a genetic, rare or undiagnosed condition. You may receive a lot of letters, test results and information from the various appointments that you have.

Efallai y byddwch chi'n dewis cadw eich nodiadau eich hun ar ddatblygiad eich plentyn. Mae'r holl bethau hyn yn wybodaeth hynod o werthfawr i chi a'r bobl sy'n rhoi gofal i'ch plentyn.

Mae'n syniad da cadw'r wybodaeth efo'i gilydd rhywle diogel fel ei bod wrth law i chi. Mae rhai teuluoedd yn cadw gwybodaeth eu plentyn mewn ffeil neu ffolder; mae'n well gan eraill gadw'r wybodaeth yn ddigidol ar ffôn neu ap.

Mae rhai teuluoedd yn trefnu eu gwaith papur yn ôl arbenigedd clinigol, ac eraill yn ôl trefn dyddiad. Mater i chi yw sut rydych chi eisiau casglu a storio gwybodaeth am eich plentyn ond mae'n syniad da meddwl am ffordd sy'n gweithio i chi.

You may also choose to keep your own notes about how you think your child is progressing. All of this is extremely valuable information to you and the people involved in your child's care.

It is a good idea to keep this information together and somewhere safe so that you can easily access it. Some families keep their child's information in a ring binder or folder; others prefer to keep the information digitally on their phone or on an app.

Some families organise their paperwork by clinical specialty, others keep everything together in date order. How you wish to gather and store your child's information is up to you but it is a good idea to think of a way that works for you.



## 3.8 Cymryd rhan mewn ymchwil

## 3.8 Participating in research



I lawer o deuluoedd sydd â phlant a phobl ifanc sydd â chyflwr genetig, prin neu heb ddiagnosis, mae ymchwil yn rhoi gobaith am driniaeth effeithiol neu wellhad i gyflwr eu plentyn.

For many families of children and young people who have a genetic, rare or undiagnosed condition, research provides hope for an effective treatment or cure for their child's condition.

Mae gwaith ymchwil yn greiddiol er mwyn deall cyflyrau genetig, prin neu heb ddiagnosis.

Yn aml, bydd teuluoedd yn ansicr beth mae ymchwil yn ei olygu. Mae Genetic Alliance UK a SWAN UK wedi cynhyrchu adnoddau defnyddiol sy'n egluro gwaith ymchwil ac arloesi.

### Sut i gael gwylodaeth am gyfleoedd ymchwil i'ch plentyn chi

#### Grwpiau i Gleifion

Mae grwpiau cymorth i gleifion yn lle gwych i gael cyngor ar waith ymchwil sy'n cael ei gynnal yn benodol i gyflwr. Mae'n syniad da cysylltu â grŵp cymorth perthnasol i weld pa wybodaeth sydd ganddynt am gyfleoedd ymchwil sydd ar gael.

#### Siarad â'ch clinigydd arbenigol

Mae'n debyg y bydd eich clinigydd arbenigol yn ymwybodol neu efallai'n rhan o gyfleoedd ymchwil i'ch plentyn. Mae'n fan cychwyn da gofyn i'ch clinigydd arbenigol pa waith ymchwil sydd ar y gweill a sut all eich plentyn fod yn rhan ohono.

#### Doeth am Iechyd Cymru

Mae Doeth am Iechyd Cymru yn brosiect sy'n ymwneud ag iechyd y boblogaeth yng Nghymru. Prifysgol Caerdydd sy'n arwain y prosiect a'r nod yw reciriwto mwy na 260,000 o aelodau dros 16 oed i gymryd rhan mewn ymchwil. Cewch fwy o wybodaeth am yr astudiaeth yma: <https://www.healthwisewales.gov.wales/?lang=cy>

#### Porth Ymchwil Afiechyd Prin

Mae'r Porth yn cyfuno astudiaethau ymchwil i afiechydon prin sy'n digwydd ar draws Cymru. Gallwch chwilio am wybodaeth am brosiectau ar afiechydon prin all fod yn perthnasol i'ch plentyn chi. Am fwy o wybodaeth, ewch ar y Porth: <https://www.walesgenepark.cardiff.ac.uk/cy/porth-ymchwil-afiechyd-prin/>

Research is fundamental in understanding genetic, rare or undiagnosed conditions.

Often families are unsure about what is involved in research. Genetic Alliance UK and SWAN UK have produced helpful resources which explain about research and innovation.

### How to find information about research opportunities for your child

#### Patient Groups

Patient support groups are an excellent source of advice on condition-specific research that is being carried out. It is a good idea to get in touch with a relevant support group to find out what information they have on available research opportunities.

#### Speak to your specialist clinician

It is likely that your specialist clinician will be aware or possibly involved in research opportunities for your child. A good starting point is to ask your specialist clinician what research is available and how your child can be involved.

#### Healthwise Wales

Healthwise Wales is a project about the health of the population of Wales. It is led by Cardiff University and aims to recruit over 260,000 participants over the age of 16 to take part in research. More information about the study can be found here: <https://www.healthwisewales.gov.wales>

#### Rare Disease Research Gateway

The Gateway brings together research studies into rare diseases happening across Wales. You can search for information about rare disease projects that may be relevant to your child. For more information, visit the Gateway: <http://www.walesgenepark.cardiff.ac.uk/gateway/>

# 3.9 Sut i gael triniaeth i'ch plentyn

## 3.9 How to access treatment for your child



I lawer o deuluoedd, mae'r her o reoli cyflwr eu plentyn o ddydd i ddydd yn waeth oherwydd nad oes triniaeth effeithiol ar gael.

For many families, the day-to-day challenges of managing their child's condition are made worse by the absence of an effective treatment.

Nid oes triniaeth drwyddedig ar gael i'r rhan fwyaf o gyflyrau genetig, prin a heb ddiagnosis.

Ble mae triniaeth wedi cael ei thrwyddedu i gyflwr prin, gall fod yn anodd i gleifion gael gafael ar y driniaeth honno oherwydd y prosesau cymhleth ar gyfer rhoi meddyginaethau ar gael ar y GIG.

Efallai y byddwch chi'n ymwybodol o driniaeth neu feddyginaeth neilltuol sydd ar gael i gyflwr eich plentyn. Mae'n bwysig trafod hyn â'ch gweithiwr gofal iechyd proffesiynol.

Bydd eich gweithiwr gofal iechyd proffesiynol yn ystyried a fyddai eich plentyn yn elwa o'r feddyginaeth. Os oes angen meddyginaeth, bydd y gweithiwr gofal iechyd proffesiynol yn siarad efo chi am eich opsiynau.

Gallwch gael mwy o wybodaeth am sut i gael meddyginaethau ar y GIG yn y daflen 'Meddyginaethau yng Nghymru: Beth yw'r driniaeth iawn i chi?'

For most genetic, rare and undiagnosed conditions, no licensed treatment is available.

Where a treatment has been licensed for a rare condition, patients may struggle to access it due to the complex processes for making medicines available on the NHS.

You may be aware of a particular treatment, or medicine, available for your child's condition. It is important to discuss this with your healthcare professional.

Your health professional will consider whether the medicine will benefit your child.

If a medicine is needed, the healthcare professional will speak to you about your options.

Further information about how to access medicines on the NHS can be found in the leaflet 'Medicines in Wales: What's the right treatment for you?'

## 3.10 Beth i'w wneud os ydych chi'n anhapus efo'r gwasanaeth a gewch chi gan GIG Cymru

## 3.10 What to do if you are unhappy with the service that you receive from NHS Wales



Weithiau, bydd teuluoedd yn dweud nad ydynt yn hapus efo'r gwasanaeth a gânt gan weithiwr meddygol proffesiynol. Weithiau, byddant yn teimlo nad oes neb wedi gwrando arnynt, neu'n teimlo bod eu dymuniadau wedi cael eu hanwybyddu.

Sometimes families report that they are not happy with the service they receive from a medical professional. Sometimes this can be because families don't feel they have been listened to, or their wishes have been ignored.

Yng Nghymru, mae'r Ddeddf Gwasanaethau Cymdeithasol a Llesiant (Cymru 2014) yn rhoi'r hawl i gleifion gael gofal iechyd a fydd yn:

- ystyried eu hanghenion
- ystyried beth fyddai'n fwyaf llesol i'w hiechyd a'u lles
- eu hannog nhw i gymryd rhan mewn penderfyniadau am eu hiechyd a'u lles
- rhoi'r wybodaeth a'r cymorth iddynt allu gwneud hyn.

Mae'r Ddeddf hefyd yn rhoi'r hawl i gleifion a theuluoedd gael adborth, codi pryderon neu gwyno am y gofal iechyd a gawsant.

### Cyngor a Chymorth i Gleifion

Mae Cyngorau lechyd Cymuned yn rhoi cyngor a chymorth hylaw a chyfrinachol am ddim i gleifion, eu gofalwyr a'u teuluoedd am ofal iechyd y GIG.

Mae Cyngorau lechyd Cymuned yn hybu ymwybyddiaeth a dealltwriaeth o hawliau a chyfrifoldebau cleifion ac yn cynghori a chefnogi pobl sy'n dymuno rhoi adborth, gwneud sylwadau, codi pryderon neu wneud cwyn am driniaeth neu ofal gan y GIG yng Nghymru.

### Gall y gwasanaeth:

- helpu chi i ddeall eich hawliau a'ch cyfrifoldebau o safbwyt claf
- rhoi gwylbodaeth, cyngor a chymorth i unrhyw un sydd eisai rhoi adborth neu gwyno am ofal iechyd gan GIG Cymru
- rhoi cymorth ymarferol efo gwneud cwyn, gan gynnwys ysgrifennu llythyrau, gwneud galwadau ffôn a'ch cefnogi chi i baratoi cyn cyfarfodydd a phan fyddwch chi yno.
- gweithio gyda'r GIG drwy ddefnyddio adborth i wella eich gofal iechyd a darpariaeth y GIG.

Gallwch hefyd gael cymorth gan eich Swyddfa Cyngor ar Bopeth leol i wneud cwyn am eich ymarferydd GIG.

In Wales, Social Services and Well-being (Wales) Act 2014 gives all patients the right that the health care they receive will:

- Consider their needs
- Consider what would most benefit their health and wellbeing
- encourage them to take part in decisions about their health and wellbeing
- provide them with the information and support to do so.

The Act also gives patients and families the right to give feedback, raise concerns or complain about the healthcare they have received.

### Patient Advice and Support

Community Health Councils (CHCs) provide free, accessible and confidential advice and support to patients, their carers and families about NHS healthcare.

CHCs promotes an awareness and understanding of the rights and responsibilities of patients and advises and supports people who wish to give feedback, make comments, raise concerns or make a complaint about treatment or care provided by the NHS in Wales.

### The service can:

- help you understand your rights and responsibilities as a patient
- provide information, advice and support for anyone who wishes to give feedback or complain about healthcare delivered by NHS Wales
- provide practical help with making a complaint, including writing letters, making phone calls and supporting you in preparing for and attending meetings
- work with the NHS by using feedback to improve your healthcare and NHS service provision.

You can also get help to make a complaint about your NHS practitioner from your local Citizens Advice Bureau.

# Eich Nodiadau

# Your Notes

