



RARE
resources
W A L E S



**4 Cymorth a gwybodaeth i rieni
a gofalwyr**

**4 Support and information for
parents and carers**

Mae Rare Resources yn gasgliad o ganllawiau gwybodaeth i deuluoedd sydd wedi cael diagnosis o gyflwr genetig neu brin yn ddiweddar, sydd ar y daith at ddiagnosis, neu sydd wedi cael gwybod bod cyflwr 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

Er mwyn gofyn am gopi caled o unrhyw un o'r canllawiau Rare Resources, cysylltwch â Genetic Alliance UK ar contactus@geneticalliance.org.uk neu 0300 124 0441.

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

To request a hard copy of any of the Rare Resources guides, please contact Genetic Alliance UK at contactus@geneticalliance.org.uk or 0300 124 0441.

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4.1 Rhieni sy'n ofalwyr

4.1 Parent carers



Rydych chi'n ofalwr os ydych chi'n darparu gofal i rywun arall am reswm arall ar wahân i'w oedran. Gallwch fod yn ofalwr hyd yn oed os ydych chi'n perthyn i'r sawl rydych chi'n gofalu amdano.

You are a carer if you provide care for another person for a reason other than because of their age. You can be a carer even if you are related to the person that you care for.

Mae rhieni plant a phobl ifanc sydd â chyflwr genetig, prin neu heb ddiagnosis, yn ofalwyr hefyd fel arfer. Maent yn aml yn cael eu galw'n 'rhieni sy'n ofalwyr'.

Os ydych chi'n rhiant sy'n ofalwr i blentyn sydd â chyflwr genetig, prin neu heb ddiagnosis, mae'n naturiol i chi roi anghenion eich plentyn o flaen eich rhai chi.

Er hynny, mae'n bwysig sylweddoli bod eich anghenion chi yn bwysig hefyd – cofiwch beth maen nhw'n ei ddweud wrthych chi ar awyren – mae angen i chi wisgo eich masg ocsigen eich hun cyn gofalu am unrhyw un arall!

'Rydw i wedi bod yn ofalwr i fy ngwraig a fy mhlentyн, ond pwy sy'n gofalu am y gofalwr?' Aelod gweithdy

Mae bod yn rhiant sy'n ofalwr yn gallu bod yn straen ac yn eich llethu ar brydau, ond mae cymorth ar gael i chi.

'Rydw i'n meddwl bod pobl yn dechrau sylweddoli pa mor werthfawr yw gofalwyr. Mae mwy a mwy o help i'w gael, dim ond i chi wybod ble i chwilio amdano – a dyna'r peth anoddaf.' Aelod gweithdy

'Pryd ydw i'n rhiant? Pryd ydw i'n ofalwr? Beth yw'r gwahaniaeth? Beth am fy mhlant eraill? A ydyn nhw'n ofalwyr hefyd?' Aelod gweithdy

Parents to children and young people who have a genetic, rare or undiagnosed condition, are also typically carers. They are often referred to as 'parent carers'.

As a parent carer to a child with a genetic, rare or undiagnosed condition, it is natural to put the needs of your child ahead of your own.

However, it is important to recognise that your needs are also important – think of what they tell you on aeroplanes – you need to fix your own oxygen mask before attending to anyone else!

'I've been a carer to both my wife and child, but who cares for the carer?' Workshop participant

Being a parent carer can sometimes feel stressful and overwhelming, but there is support available to you.

'I think people are starting to recognise just how valuable carers are. There is more and more help out there, it's just knowing where to find it – and that's the hard part.' Workshop participant

'When am I a parent? When am I a carer? What's the difference? What about my other children? Are they carers too?' Workshop participant

Cyngor Gan Rieni

Cyfarfod â rhieni eraill sy'n ofalwyr – Gall fod ynfuddiol iawn cyfarfod ag eraill sydd wedi, neu wrthi'n cael profiad o'r hyn rydych chi'n mynd drwyddo.

Deall eich hawliau fel gofalwr – Nid yw llawer o rieni yn sylweddoli mai nhw yw gofalwyr eu plant hefyd, felly nid ydint yn manteisio ar y cymorth ymarferol, emosional ac ariannol sydd ar gael iddynt.

Peidio â bod ofn gofyn am help – Cofiwch, mae'n gwbl naturiol i chi deimlo fod popeth yn ormod o bryd i'w gilydd. Peidiwch â bod ofn gofyn am help pan fydd ei angen arnoch.

Gwneud amser i chi'ch hun – Gall hyn fod yn ychydig o amser pob dydd, neu'n rhyw ddwyawr yr wythnos.

Cofio pwy ydych chi – Rydych chi'n fwya na rhiant sy'n ofalwr. Ceisiwch wneud amser i chi'ch hun a'r pethau sy'n rhoi mwynhad i chi. Hyd yn oed os mai ychydig funudau ydi hynny. Os nad yw hyn yn bobis, yna ceisiwch wneud pethau bach all helpu tra byddwch chi wrthi'n gwneud tasgau eraill – er enghraifft, mynd i'r toiled fel cyfle i stopio ac anadlu allan yn ddfon ddeg gwaith i ymlacio.

Top Tips From Parents

Meet other parent carers – It can be very beneficial to meet others who are experiencing, or have experienced what you are going through.

Understand your rights as a carer – Many parents are unaware that they are also carers for their child, and as a result miss out on the practical, emotional and financial support available to them.

Don't be afraid to ask for help – Remember it is completely normal to feel overwhelmed from time to time. Don't be afraid to ask for help when you need it.

Make time for yourself – This can be a little time each day, or a couple of hours a week.

Remember who you are – You are not only a parent carer. Try to make time for yourself and the things that you enjoy even if it is just for a few minutes. If this isn't possible then try and find ways to fit in small things that can help while you are doing other tasks – for example, use going to the bathroom as a chance to stop and count ten deep exhalations to relax you.

4.2 Eich hawliau a'ch anghenion yn ofalwr

4.2 Your rights and needs as a carer



Yng Nghymru, mae gan ofalwyr hawliau dan y Ddeddf Gwasanaethau Cymdeithasol a Llesiant (Cymru) 2014. Yn rhiant sy'n ofalwr yng Nghymru, mae gennych yr hawl i gael asesiad o'ch anghenion o safbwyt bod yn ofalwr gan eich cyngor lleol.

In Wales, carers have rights under the Social Services and Well-being (Wales) Act 2014. As a parent carer in Wales, you are entitled to a carers' needs assessment of your needs by your local council.

Bydd asesiad anghenion yn cael ei wneud os gwelir bod angen cymorth arnoch chi, neu eich bod chi'n debygol o fod angen cymorth yn y dyfodol. Gallwch hefyd ofyn i'ch cyngor lleol am asesiad anghenion. Os bydd eich cyngor lleol yn penderfynu bod eich anghenion yn gymwys, yna mae gan y cyngor rwymedigaeth gyfreithiol i fodloni'r anghenion hynny, os ydych chi am iddynt wneud hynny. Bydd rhaid llunio cynllun cymorth sy'n manylu ar sut fydd yr anghenion hyn yn cael eu bodloni a rhaid i gopi o hwn gael ei gynnig i chi.

Efallai bydd eich cyngor lleol yn gallu trefnu cymorth ymarferol i chi. Gall hyn gynnwys:

- Gwybodaeth a chyngor
- Cymorth gan ofalwyr eraill neu sefydliadau i ofalwyr
- Seibiant o'ch cyfrifoldebau yn gofalu
- Cymorth emosiynol
- Cyrsiau hyfforddi i ofalwyr
- Help i wneud cais am fudd-daliadau ariannol

Beth yw asesiad anghenion gofalwr?

Bydd yr asesiad yn ystyried a yw eich rôl yn gofalu yn effeithio ar eich iechyd neu'n eich atal chi rhag cyflawni eich deilliannau lles neu beidio. Er enghraift, gallai hyn olygu aros yn y gwaith, cael bywyd cymdeithasol, gallu mynd i awpyntiadau meddygol neu wneud rhywfaint o weithgareddau hamdden. Dylai'r asesiad edrych ar: eich rôl yn gofalu a sut mae'n effeithio ar eich bywyd, eich lles a'ch iechyd – yn gorfforol, yn feddyliol ac yn emosiynol – eich teimladau a'ch dewisiadau o ran gofalu, astudio, hyfforddi, hamdden, perthynas ag eraill gweithgareddau cymdeithasol a'ch nodau, a chynllun am gartref mewn argyfwng.

Bydd yr asesiad yn asesu pa gymorth y gall fod ei angen arnoch chi i'ch helpu chi i ofalu. Mae'r Ddeddf Gwasanaethau Cymdeithasol a Llesiant (Cymru) yn cyflwyno'r rheolau cenedlaethol ar gyfer penderfynu pwysydd yn gymwys i gael gofal a chymorth. Y cyngor lleol a fydd yn penderfynu a yw eich anghenion yn gymwys dan y rheolau cymhwysedd ac a oes gan y cyngor rwymedigaeth gyfreithiol i'w diwallu.

Dylai cynllun cymorth gael ei lunio sy'n nodi eich anghenion a sut y byddant yn cael eu diwallu.

This will be triggered if it appears that you may need support or are likely to do so in the future. You can also ask your local council for a needs assessment. If your local council decides that your needs are eligible, then providing that you want them to, they have a legal obligation to meet these needs. A support plan must be drawn up detailing how these needs will be met and a copy must be offered to you.

Your local council may be able to arrange practical help for you. This may include:

- Information and advice
- Support from other carers or carer organisations
- A break from your caring responsibilities
- Emotional help
- Carer training courses
- Help applying for financial benefits

What is a carer's needs assessment?

The assessment will consider whether or not your caring role impacts on your health or prevents you from achieving your well-being outcomes. As an example this could be staying in work, having a social life, being able to attend medical appointments or doing some leisure activities. The assessment should cover: your caring role and how it affects your life and well-being, your health – physical, mental and emotional issues – your feelings and choices about caring work, study, training, leisure relationships, social activities and your goals, and housing planning for emergencies.

The assessment will assess what support you might need to help you in your role as a carer. The Social Services and Well-being (Wales) Act introduces national rules for deciding who is eligible for care and support. It will be the local council who decides whether your needs are eligible under the eligibility rules and whether they have a legal obligation to meet them.

A support plan should be written setting out your needs and how they will be met.

Hawliau Gofalwyr sy'n Gweithio

Gall rhieni a gofalwyr sy'n gweithio hefyd fod yn gymwys i gael budd-daliadau mewn gwaith neu gredyddau treth. Siaradwch ag ymgynghorydd budd-daliadau cyn i chi ddychwelyd i'r gwaith. Gallant roi cyngor a chymorth i chi ar sut y bydd dychwelyd i'r gwaith yn effeithio ar eich hawl i fudd-daliadau.

Efallai y byddwch chi'n gallu cael cymorth gan eich cyflogwr i gydwyso eich anghenion gofalu â'ch gwaith. Gallai hyn gynnwys opsiynau gweithio'n hyblyg, gwyliau â thâl neu wyliau heb dâl. Cysylltwch â'r ganolfan i ofalwyr sy'n lleol i chi am gyngor.

Lwfans Gofalwr

Lwfans Gofalwr yw'r prif nawdd cymdeithasol i ofalwyr ac mae hwn ar gyfer unrhyw un sy'n treulio o leiaf 35 awr yr wythnos yn rhoi gofal rheolaidd i rywun.

Gallwch fod â'r hawl i gael Lwfans Gofalwr os yw eich plentyn yn cael cyfradd ganol neu uwch elfen ofal y Lwfans Byw i'r Anabl. Nid yw Lwfans Gofalwr yn dibynnu ar brawf modd, ond mae'r hyn rydych chi'n ei ennill yn gallu effeithio ar faint allwch chi ei gael.

Cyngor Gan Rieni

Mae'n syniad da paratoi am eich trafodaeth ar y Cynllun Cymorth i Ofalwyr. Treuliwch ychydig o amser yn meddwl am y pwyntiau sydd wedi'u rhestru uchod. Gallwch gael cyngor ar y Cynllun hwn drwy gysylltu â'ch corff lleol i ofalwyr.

Rights for Working Carers

Parents and carers who also work may be entitled to in-work benefits or tax credits. Speak to a benefits advisor before returning to work. They can provide you with advice and support on how returning to work will affect your entitlement to benefits.

You may be able to get support from your employer to balance your caring needs with work. This could include flexible working options, paid or unpaid leave. Contact your local carers centre for advice.

Carer's Allowance

Carer's Allowance is the main social security support for carers and is for anyone who spends at least 35 hours per week providing regular care to someone.

You may be entitled to Carer's Allowance if your child receives the middle or high rate care component of Disability Living Allowance. Carer's Allowance is not means tested, but what you earn may affect how much you are entitled to.

Top Tips From Parents

It is a good idea to prepare for your Adult Carer Support Plan conversation. Spend some time considering the points listed above. You can obtain advice on the Adult Carer Support Plan by contacting your local carer organisation.



4.3 Cymorth i ofalwyr

4.3 Support for carers

Mae nifer o sefydliadau i ofalwyr sy'n darparu gwybodaeth, cyngor a chymorth i ofalwyr yng Nghymru.

There are a number of carers organisations that provide information, advice and support to carers in Wales.

Mae'r rhain yn cynnwys:

Carers Wales –
carersuk.org/wales
029 2081 1370
info@carerswales.org

Carers Trust Wales –
0300 772 9702
carers.org
wales@carers.org

Mae'r Samariaid yn rhoi cymorth emosiynol i unrhyw un sy'n ei chael hi'n anodd i ymdopi, ar eu llinell gymorth a'u gwefan –
116 123
bit.ly/rrsamaritans

Rhaid i bob cyngor lleol hefyd ddarparu gwasanaeth gwybodaeth a chyngor i ofalwyr. Cewch fwy o wybodaeth am y gwasanaeth yn eich ardal chi drwy gysylltu â'ch cyngor lleol.

These include:

Carers Wales –
carersuk.org/wales
029 2081 1370
info@carerswales.org

Carers Trust Wales –
0300 772 9702
carers.org
wales@carers.org

The Samaritans provide emotional support to anyone struggling to cope, through their telephone helpline and website –
116 123
bit.ly/rrsamaritans

Each local council must also provide an information and advice service for carers. You can find out more about the service in your area by contacting your local council.



4.4 Chwilio am gymorth gan rieni a gofalwyr eraill

4.4 Find support from other parents and carers



Gall fod yn gysur ac yn help siarad efo rhywun sydd â'r un cyflwr, neu sydd â phlentyn â'r un cyflwr – rhywun sydd â phrofiad o'r un pethau rydych chi'n eu hwynnebu.

It can be comforting and helpful to talk to someone with, or who has a child with, the same condition – someone who has experienced the same things that you are facing.

Mae byw gyda chyflwr prin (ac mae'r rhan fwyaf o gyflyrâu genetig yn rhai prin) yn gallu bod yn beth unig iawn oherwydd nad oes gan lawer o bobl eraill yr un cyflwr. Mae'r un yn wir am fod yn rhiant, yn ofalwr neu'n aelod teulu i rhywun sydd â chyflwr genetig, prin neu heb ddiagnosis.

Y ffordd orau i geisio chwilio am rieni a theuluoedd eraill yw drwy sefydliad i gleifion ar gyfer cyflwr eich plentyn. Mae sefydliadau i gleifion yno i gefnogi plant, teuluoedd, unigolion a gofalwyr. Maent yn arbenigo ar ddeall eu cyflyrâu penodol ac ar roi'r cymorth sydd ei angen arnoch chi.

Fforymâu ar-lein

Mae'r we yn gartref i gyfoeth o lefydd rhithiol i bobl gyfarfod a siarad am eu profiadau â chyflyrâu genetig, prin a heb ddiagnosis. Dyma rai adnoddau dibynnadwy:

Facebook

Yn llwyfan anffurfiol sy'n rhad ac am ddim, mae Facebook yn gartref i nifer o grwpiau cymorth ar-lein. Nid oes angen i chi gael cyfrif Facebook i chwilio am grwpiau, ond bydd angen i chi gofrestru i ymuno a siarad â phobl os byddwch chi'n dod o hyd i grŵp perthnasol. Os nad oes grŵp Facebook ar gyfer y cyflwr, gallech chi ddechrau un ar gyfer pwy bynnag fydd yn chwilio am un y tro nesaf. Gall fod yn ffordd wych i gysylltu ag eraill yn uniongyrchol.

Cymuned Ar-lein Contact

Mae Cymuned Ar-lein Contact yn fforwm ar-lein sydd wedi'i ffurfio gan Contact i rieni plant sydd ag anableddau. Teipiwch eich cyflwr yn y bocs chwilio ar y wefan i weld faint o bobl sydd wedi cofrestru dan enw'r cyflwr. Cofiwch gofrestru eich hun, hyd yn oed os nad oes neb arall wedi cofrestru, fel bod unrhyw un sydd newydd gael diagnosis yn gallu dod o hyd i chi.

Rare Connect

Mae Rare Connect yn llwyfan ar-lein, rhad ac am ddim, sydd â chymunedau sy'n benodol i gyflyrâu a grwpiau trafodaeth cyffredinol. EURORDIS oedd yn gyfrifol am greu'r llwyfan sef cynghrair o sefydliadau i gleifion â chlefydau prin yn Ewrop. Mae trafodaethau yn cael eu cyfieithu mewn chwe iaith (Saesneg, Ffrangeg, Almaeneg, Eidaleg, Sbaeneg a Phortiwgaleg).

Having a rare condition (which most genetic conditions are) can feel extremely isolating because there aren't many other people out there living with the condition. The same goes for being a parent, carer or family member to someone with a genetic, rare or undiagnosed condition.

The best way to try and find other parents and families is through a patient organisation for your child's condition. Patient organisations exist to support children, families, individuals and carers. They are experts in understanding their specific conditions and at providing the support that you need.

Online forums

The internet is home to a wealth of virtual areas for people to meet and talk about their experiences with genetic, rare and undiagnosed conditions. Some trusted resources include:

Facebook

As a free, informal platform Facebook is home to a number of online support groups. You don't need to have a Facebook account to search for groups, although if you do find a relevant group you will need to sign up to join and talk to people. If there isn't already a Facebook group for the condition you can always set one up for the next person who is searching for one. It can be a great way to connect with others directly.

Contact Online Community

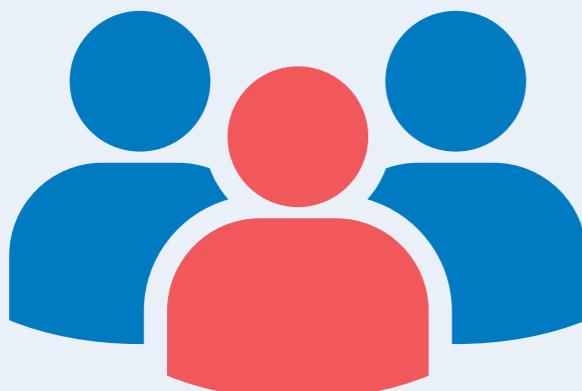
Contact Online Community is an online forum set up by the organisation Contact for parents of children with disabilities. Just enter your condition into the search function on the website and you'll be able to see how many people have registered under the condition name. Don't forget to register yourself, even if there isn't anyone else registered, so that anyone who is newly diagnosed can find you.

Rare Connect

Rare Connect is a free online platform with condition specific communities and general discussion groups. The platform was set up by EURORDIS: an alliance of rare disease patient organisations in Europe. Discussions are translated across six languages (English, French, German, Italian, Spanish and Portuguese).

4.5 Rheoli perthynas ag eraill

4.5 Managing relationships



Mae ein perthynas ag eraill yn gallu chwarae rhan fawr yn ein bywydau ac yn rhoi cysur, anogaeth, help a chymorth, yn emosiynol ac yn ymarferol.

Our relationships with others can play a big part in our lives and can provide comfort, encouragement, help and support, both emotionally and practically.

I lawer o rieni, gall eu perthynas ag eraill wneud gwahaniaeth i'w hiechyd a'u lles.

Er hynny, mae gofalu am blentyn neu berson ifanc sydd â chyflwr genetig, prin neu heb ddiagnosis yn gallu golygu heriau a phwysau newydd. Gall hyn rhoi straen ar berthynas weithiau.

Eich perthynas

I rai cyplau, gall y profiad o fagu plentyn sydd â chyflwr genetig, prin neu heb ddiagnosis eu llethu.

Yn ôl rhai cyplau, mae'r profiad yn dod â nhw'n agosach at ei gilydd, ond i eraill mae'r profiad yn gallu rhoi straen ar eu perthynas. Mae pob unigolyn a phob cwpl yn wahanol a gall pethau newid dros amser hefyd.

Rhieni sengl

Mae bod yn rhiant sengl i blentyn sydd â chyflwr iechyd yn gallu golygu mwy o gyfrifoldebau. Mae cymorth ar gael i rieni sengl gan sefydliadau fel Gingerbread.

Teulu a ffrindiau

Mae honno'n sgwrs anodd, pan fyddwch chi'n dweud wrth aelodau'r teulu a ffrindiau am ddiagnosis cyflwr genetig, prin neu heb ddiagnosis.

Efallai y byddwch chi'n poeni beth fydd gan eich teulu i'w ddweud, a fyddant yn deall neu beidio neu'n ddigalon.

Y peth pwysig i'w gofio yw mai eich penderfyniad chi yw dweud wrth aelodau o'ch teulu, neu ddim, a chi sydd i benderfynu sut orau i wneud hyn.

Beth os fydd angen help arnom ni?

Mae pob un ohonom ni yn gobeithio bod ein perthynas ni'n ddigon cryf i'n helpu ni ddod dros rhai o'r heriau yn ein bywyd. I rai, mae'r her o gael plentyn sydd â chyflwr iechyd yn gallu cryfhau eu perthynas.

Yn anffodus, nid felly mae hi pob tro a gall ambell i berthynas newid.

Efallai y byddai'n gymorth cael cyngor proffesiynol annibynnol.

Gall hyn fod ar ffurf gwasanaethau cwnsela neu gyfryngu.

For many parents, their relationships with others can make a difference to their health and wellbeing.

However, caring for a child or young person with a genetic, rare or undiagnosed condition can bring new challenges and pressures, and sometimes this can put strain on relationships.

Your relationship

For some couples, the experience of raising a child with a genetic, rare or undiagnosed condition can be overwhelming.

Some couples report that the experience brings them closer together, whilst for others, the experience can put a strain on their relationship. Every person, and every couple, is different and it may also change over time.

Single parents

Being a single parent to a child with a health condition can bring additional responsibilities. There is support available to single parents from organisations such as Gingerbread.

Families and friends

Telling family members and friends about the diagnosis of a genetic, rare or undiagnosed condition can be a difficult conversation.

You may be worried about what your family members might say, whether or not they will be understanding or whether they will be upset.

The important thing to remember is that telling your family members is your decision to make, and it is up to you how you choose to do it.

What if we need help?

We all hope that our relationships are strong enough to help us overcome some of the challenges in our life. For some, the challenges of having a child with a health condition can strengthen their relationships.

Unfortunately, this is not always the case and some relationships can change.

It may be that it would be helpful to seek some independent, professional advice.

This can be in the form of counselling or mediation services.

Cyngor Gan Rieni

Siaradwch a Gwrandewch. Peidiwch â bod ofn cyfleo eich teimladau a siarad efo'ch partner pan fyddwch chi'n poeni. Cofiwch, mae gwahanol bobl yn prosesu ac yn delio gyda'u teimladau mewn ffyrdd gwahanol – mae'n bwysig gwrandeo ar eich gilydd a pharchu teimladau y naill a'r llall.

Siaradwch am y dyfodol. Mae'n bwysig rhannu eich pryderon am y dyfodol efo'ch partner. Cofiwch fod yn bositif – mae llawer o adegau hapus i'w cael efo'ch plentyn. Treuliwch amser yn cynllunio pethau hwyliog i'w gwneud gyda'ch gilydd, ac fel teulu.

Fe wnewch chi ffrindiau newydd. Mae'n debyg y gnewch chi gyfarfod â theuluoedd newydd sydd wedi cael yr un profiadau â chi. Dyma gyfle i wneud ffrindiau newydd.

Peidiwch â synnu. Mae pawb ohonom yn prosesu gwybodaeth a'n teimladau mewn ffyrdd gwahanol iawn. Peidiwch â synnu neu ddiglonni os bydd aelodau o'r teulu, yr ydych chi'n dewis dweud wrthynt, yn ymateb yn wahanol i sut yr oeddech chi wedi'i ddisgwyl. Byddwch yn barod i roi lle ac amser iddynt gymryd yr wybodaeth i mewn yn eu hamser eu hunain.

Cymerwch eich amser. Os nad ydych chi'n barod i gynnwys ffrindiau neu deulu yn syth, mae hynny'n iawn. Cymerwch ychydig o amser i feddwl wrth bwy rydych chi eisiau dweud, sut rydych chi eisiau dweud wrthynt a'r adeg gorau i wneud hynny.

Peidiwch â gadael i ddiagnosis gael y gorau ar eich perthynas. Cofiwch fod pethau eraill yn digwydd yn eich bywyd ac ym mywydau eich teulu. Mae'n bwysig siarad am y pethau da a chalonogol sy'n digwydd yn eich bywyd.

Daliwch at i wneud pethau sy'n bwysig i chi. Mae'n gallu bod yn hawdd tynnu'n ôl o'r pethau sy'n bwysig i chi (er enghraifft, gwneud chwaraeon neu gyfarfod â ffrind yn rheolaidd). Gall fod yn hawdd hoolio eich holl sylw ar eich plentyn ac mae'n gyffredin i chi deimlo'n rhy flinedig i wneud y pethau roeddech chi'n arfer eu gwneud yn rheolaidd. Ond, mae gwneud pethau er eich mwyn chi a chynnal y perthnasoedd sy'n bwysig i chi, yn bwysig iawn i'ch lles chi ac mae'n syniad da ceisio gwneud o leiaf un peth sy'n bwysig i chi, a dim ond ar eich cyfer chi.

Top Tips From Parents

Talk and listen. Don't be afraid to express your feelings and talk to your partner when you have concerns. Remember, different people process and deal with their thoughts and feelings in different ways – it is important to listen to each other and respect each other's feelings.

Talk about the future. It is important to share your worries for the future with your partner. Don't forget to be positive – there are many happy moments to be had with your child. Spend time planning fun things you can do together, and as a family.

You will make new friends. You will likely meet new families who have shared similar experiences to you. This is an opportunity to make new friendships.

Make allowances. We all process information and our feelings in very different ways. Don't be surprised or upset if the family member you are telling doesn't react the way that you expect them to. Be prepared to give them some time and space to process the information at their own pace.

Take your time. If you are not ready to involve friends or family straight away, that is ok. Take a little time to consider who you want to tell, how you want to tell them and think about the best time to do it.

Don't let diagnosis dominate your relationships. Remember that other things go on in your life and in the lives of your family. It's important to talk about good and positive things that are happening in your lives.

Continue to do things that are important to you. It can be easy to withdraw from some of the things that are important to you (for example, playing sport or a regular meet up with a friend). It can be easy to focus all your attention on your child and it is not uncommon to feel too tired to do the things you were used to doing regularly. However, doing things for you and maintaining the relationships you value is very important to your wellbeing and it's a good idea to try and do at least one thing that is important to you, and is just for you.



4.6 Cymryd seibiant

4.6 Taking a break

Bydd adegau pan fydd eich cyfrifoldebau gofalu yn gallu bod yn flinedig tu hwnt a phan allai wneud lles i chi, neu chi a'ch partner, gymryd amser i ffwrdd o'ch rôl yn gofalu.

There will be times when your caring responsibilities can become exhausting and it might be good for you, or you and your partner, to have a short time away from your caring role.

Mae hyn yn cael ei alw'n seibiant byr neu'n ofal seibiant weithiau.

Gall seibiant byr fod yn rhan hanfodol o'r cymorth sydd ei angen ar deuluoedd yn gyffredinol. Gall seibiant dorri ar y patrwm dyddiol, rhoi amser i orffwys ac ail-gyfnerthu a rhoi cyfle i dreulio amser ag eraill neu wneud rhywbeth sydd o ddiddordeb i chi.

Mae gwahanol fathau o seibiannau byr a gofal seibiant, gan gynnwys:

- Gwyliau neu wyliau gweithgareddau
- Gofal i'ch plentyn mewn canolfan ddydd
- Cynlluniau chwarae arbenigol neu glybiau ar ôl ysgol
- Cyllid i chi wneud rhywbeth yr hoffech chi ei wneud, fel therapiâu ymlacio neu fynd i'r sinema

Efallai y byddwch chi'n gallu cael seibiant byr neu ofal seibiant drwy eich cyngor lleol. Byddwch yn trafod eich anghenion seibiant yn eich asesiad anghenion. Mae elusennau a chyrff trydydd sector hefyd sy'n rhoi seibiant neu grantiau am seibiant byr.

This is sometimes called a short break or respite care.

Short breaks or respite can be an essential part of the overall support that families need, they can provide a break from routine, time to rest and recharge, and opportunities to spend time with others or pursue your own interests.

Short breaks and respite care can come in many different forms including:

- Holiday or activity breaks
- Care for your child at a day centre
- Specialist play schemes or after school clubs
- Funding for you to do something you would like to do, such as relaxation therapies or going to the cinema

You may be able to access a short break or respite care through your local council. You will have a discussion about your respite needs as part of your needs assessment. There are also charities and third sector organisations that provide respite or grants for short breaks.



4.7 Cymorth efo sefyllfa ariannol

4.7 Help with finances

Mae gofalu am blentyn sydd â chyflwr genetig, prin neu heb ddiagnosis yn gallu effeithio ar sefyllfa ariannol eich teulu ac efallai y byddwch chi eisbau mynd ati i geisio cael cymorth ariannol.

A chithau'n ofalwr, gallwch fod â'r hawl i gael budd-daliadau lles. Taliadau gan y llywodraeth yw budd-daliadau a chredydau treth. Maen nhw'n cael eu rhoi ar gyfer anghenion penodol neu bobl sydd ar incwm isel.

Mae'r rhan fwyaf o fudd-daliadau yn amodol ar feini prawf cymhwysedd ac yn seiliedig ar eich amgylchiadau personol.

Mae'n syniad da cael cyngor gan ymgynghorydd budd-daliadau lles i gael gwybod am y math o gymorth ariannol y gallech fod â'r hawl i'w gael.



Caring for a child with a genetic, rare or undiagnosed condition may have an impact on your family's finances and you may wish to try to access financial support.

As a carer, you may be entitled to welfare benefits. Benefits and tax credits are payments from the government. They may be given to meet specific needs or to people on a low income.

Most benefits are subject to eligibility criteria and based on your own personal circumstances.

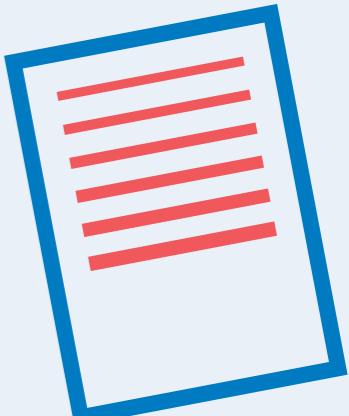
It is a good idea to seek advice from a welfare benefits advisor to obtain information on what type of financial support you may be eligible for.

4.8 Safonau lechyd a Gofal Cymdeithasol

4.8 Health and Social Care Standards

Mae'r Safonau lechyd a Gofal Cymdeithasol yn nodi'r hyn y dylen ni ddisgwyl wrth ddefnyddio gwasanaethau iechyd, gofal cymdeithasol neu waith cymdeithasol yng Nghymru. Mae'r Safonau yn berthnasol i amrywiaeth eang o wasanaethau o warchod plant a gofal dydd i blant yn eu blynnyddoedd cynnar, cymorth tai a gofal yn y cartref, hyd at ysbytai, clinigau a chartrefi gofal.

The Health and Care Standards set out what we should expect when using health, social care or social work services in Wales. The Standards can be applied to a diverse range of services from child-minding and daycare for children in their early years, housing support and care at home, to hospitals, clinics and care homes.



4.9 Eiriolaeth a chyfryngu

4.9 Advocacy and mediation

Mae eiriolaeth yn wasanaeth sydd yn ceisio sicrhau bod llais pobl yn cael ei glywed, a bod eu hawliau yn cael eu hystyried ar faterion sy'n bwysig iddynt.

Gall eiriolwr eich cefnogi chi i fynegi eich barn. Gall roi cymorth mewn person i chi drwy ddod i gyfarfodydd efo chi, ysgrifennu llythyrau ar eich rhan neu siarad ar eich rhan mewn sefyllfaoedd ble nad ydych chi'n teimlo'n gyfforddus yn siarad drosoch eich hun.



Mae Advocacy Matters Wales yn darparu gwasanaethau eiriolaeth annibynnol yng Nghymru.
02920233733
advocacymatterswales.co.uk

Mae cyfryngu yn broses ar gyfer datrys anghydfod sydd fel arfer yn cynnwys trydydd person annibynnol, sef y cyfryngwr. Mae'r cyfryngwr yn gadael i bawb sy'n rhan o'r anghydfod gael dweud eu dweud ac yn hwyluso trafodaeth i geisio cyrraedd cytundeb. Mae nifer o sefydliadau yn cynnig gwasanaethau cyfryngu. Mae'r Family Mediation Council yn rhoi gwybodaeth am y broses a chyfeiriadur o wasanaethau cyfryngu yn y DU.
familymediationcouncil.org.uk
01707 594055

Advocacy is a service which seeks to ensure that people have their voice heard, and rights considered, on issues that are important to them.

An advocate can support you to express your views. They may support you in person by attending meetings with you, writing letters on your behalf or speaking for you in situations that you do not feel comfortable speaking for yourself.



Advocacy Matters Wales provides independent advocacy services in Wales.
02920233733
advocacymatterswales.co.uk

Mediation is a process for settling disputes typically involving an independent third party known as a mediator. The mediator allows all parties involved in the dispute to have their say and facilitates discussion to try and reach an agreement. A number of organisations offer mediation services. The Family Mediation Council provides information on the process of mediation and a register of mediation services in the UK.
familymediationcouncil.org.uk
01707 594055



Eich Nodiadau

Your Notes

