RARE resources WALES

8 Canllaw i Weithwyr Proffesiynol

8 Professionals' Guide

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/rareresourceswales

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/rareresourceswales

8.1 Cyflwyniad

8.1 Introduction

Genetic Alliance UK sydd wedi cynhyrchu'r Adnoddau Prin ochr yn ochr â theuluoedd. Mae'r adnoddau yn rhoi gwybodaeth gyffredinol am gyflyrau prin, genetig a heb ddiagnosis.

Rare Resources has been produced by Genetic Alliance UK, in collaboration with families, and provides general information on rare, genetic and undiagnosed conditions.

Mae'r adnoddau yn llawn gwybodaeth ddefnyddiol i helpu gweithwyr proffesiynol ddeall eu hanghenion yn well a sut i helpu teuluoedd i gael gofal, gwybodaeth a chymorth priodol.

Gall yr adnoddau fod yn arbennig o ddefnyddiol i weithwyr iechyd a gofal cymdeithasol proffesiynol, darparwyr addysg a gweithwyr cefnogi teuluoedd.

It includes valuable information to help professionals better understand the needs of families and provides information on how to assist families to access appropriate care, information and support.

It may be particularly useful for health and social care professionals, education providers and family support workers.

8.2 Cyflyrau genetig, prin a heb ddiagnosis

8.2 Genetic, rare and undiagnosed conditions

Mae cyflyrau genetig, prin neu heb ddiagnosis yn gallu amrywio'n fawr o ran yr effaith a gânt ac maent yn gallu effeithio ar lawer o agweddau ar fywyd teuluol.

The effects of having a genetic, rare or undiagnosed condition can be very varied and can affect many aspects of family life.

Mae llawer o wahanol fathau o gyflyrau genetig a phrin, a bydd y ffordd y bydd cyflwr yn effeithio ar deulu yn dibynnu ar nifer o ffactorau. Er hynny, nid yw'n anghyffredin i deuluoedd plant a phobl ifanc sydd â chyflyrau genetig, prin a heb ddiagnosis wynebu'r un math o heriau.

Mae'r rhain yn aml yn cynnwys:
- taith hir at ddiagnosis
- ansicrwydd am y dyfodol
- diffyg dealltwriaeth gan weithwyr proffesiynol sy'n rhan o ofal eu plentyn
- gofal wedi'i drefnu'n wael, llawer o wahanol weithwyr gofal iechyd proffesiynol yn rhoi gofal a llawer o apwyntiadau
- trafferth cael gwybodaeth a chymorth gan arbenigwr, neu grŵp i gleifion, ar gyfer cyflwr eu plentyn
- teimlo'n unig

Yn aml, bydd cyflyrau genetig, prin, a heb ddiagnosis yn rhai cronig ac yn effeithio ar fwy nag un rhan o'r corff. O ganlyniad, bydd angen gofal cymhleth ar blant sydd â'r cyflyrau hyn gan wahanol weithwyr iechyd proffesiynol.

Mae'r gofal a'r driniaeth i lawer o deuluoedd wedi'u trefnu'n wael. Caiff hyn effaith andwyol ar ofal y plentyn a bywyd y teulu. Yn aml, gall teuluoedd deimlo'n rhwystredig oherwydd diffyg dealltwriaeth o'r cyflwr genetig, prin neu heb ddiagnosis gan y rheiny sy'n rhan o ofal eu plentyn.

Mae'n bwysig bod gweithwyr proffesiynol sy'n rhan o ofal plentyn neu berson ifanc yn adnabod anghenion ychwanegol teuluoedd sy'n byw â chyflwr genetig, prin neu heb ddiagnosis.

There are many different types of genetic and rare conditions and how a condition affects a family will depend on a number of factors, however it is not uncommon for families of children and young people with genetic, rare and undiagnosed conditions to experience similar challenges.

These often include:
- a long journey to diagnosis
- uncertainty about the future
- lack of understanding from professionals involved in the care of their child
- poorly coordinated care, lots of different healthcare professionals involved and lots of appointments
- difficulties in accessing information and support from an expert, or patient group, for their child's condition
- experiencing feelings of isolation

Often genetic, rare and undiagnosed conditions are chronic and affect multiple parts of the body. Consequently, children with these conditions require complex care from a range of different health professionals.

Many families experience care and treatment that is poorly coordinated. This has a detrimental impact on their care and the lives of their families. Families can often feel frustrated by the lack of understanding of the genetic, rare or undiagnosed condition by those involved in the care of their child.

It is important for professionals involved in the care of a child or young person to recognise the additional needs of families living with a genetic, rare or undiagnosed condition.

8.3 **Pecyn Adnoddau Prin**

8.3 **Rare resources toolkit**

Canllaw yw Adnoddau Prin sydd wedi'i gynhyrchu gan Genetic Alliance UK i deuluoedd sydd wedi cael diagnosis o gyflwr genetig neu brin yn ddiweddar, sydd ar y daith at gael diagnosis, neu sydd wedi cael gwybod bod cyflwr eu plentyn mor brin na chaiff ddiagnosis, o bosib. Gall gweithwyr proffesiynol sydd yn gofalu am blentyn neu berson ifanc hefyd ddefnyddio'r pecyn i gyfeirio teuluoedd at ofal a chymorth priodol.

Rare Resources is a guide produced by Genetic Alliance UK for families who have recently received a diagnosis of a genetic or rare condition, are on the journey to a diagnosis, or who have been told their child's condition is so rare they might not get a diagnosis. The Toolkit can also be used by professionals in the care of a child or young person to signpost families to appropriate care and support.

Yn y Pecyn, mae amrywiaeth fawr o wybodaeth gyffredinol am gyflyrau genetig, prin a heb ddiagnosis yn ogystal â gwybodaeth ar sut i gael gwybodaeth, gofal a chymorth sy'n ddibynadwy.

Dyma'r adrannau sydd yn y pecyn:

- Eglurhad o gyflyrau genetig, prin a heb ddiagnosis.
- Y daith at gael diagnosis.
- Cymorth a gwybodaeth i rieni a gofalwyr.
- Cymorth a gwybodaeth i'ch plentyn.
- Defnyddio'r GIG yng Nghymru.
- Cyfeiriadur gwybodaeth efo manylion y gwasanaethau cymorth sydd ar gael yng Nghymru.

Gallwch lawr lwytho'r Pecyn Adnoddau Prin o bit.ly/rareresourcesWales

Cefnogi teuluoedd y mae cyflyrau genetig, prin a heb ddiagnosis yn effeithio arnynt

Drwy gydol eich gyrfa, mae'n debyg y byddwch chi'n gweithio gyda theuluoedd plant sydd â chyflwr genetig, prin neu heb ddiagnosis. Er na fydd hi'n bosib i chi wybod am bob cyflwr genetig, prin a heb ddiagnosis, bydd yn ddefnyddiol i chi adnabod yr heriau ychwanegol sy'n wynebu teuluoedd ac ystyried y cyngor ar y dudalen nesaf pan fyddwch chi'n cynnig cymorth.

The Toolkit contains a wide range of general information on genetic, rare and undiagnosed conditions as well as information on how to access reliable information, care and support.

The Toolkit includes the following sections:

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

The Rare Resources Toolkit can be downloaded from bit.ly/rareresourcesWales

Supporting families affected by genetic, rare and undiagnosed conditions

It is likely that you will work with families with a child with a genetic, rare or undiagnosed condition throughout your career. Although it will not be possible to have knowledge of all genetic, rare and undiagnosed conditions, it will be useful to recognise the additional challenges families face and consider the top tips on the next page when offering support.

8.4 Mwy o wybodaeth

8.4 Further information

Genetic Alliance UK
bit.ly/rrgeneticallianceuk

Rare Disease UK
bit.ly/rrrarediseaseuk

SWAN UK (syndromes without a name)
bit.ly/rrswanuk

Your Genome
yourgenome.org

Contact a Family
contact.org.uk

Orphanet
orpha.net

Genetic Alliance UK
bit.ly/rrgeneticallianceuk

Rare Disease UK
bit.ly/rrrarediseaseuk

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bit.ly/rrswanuk

Your Genome
yourgenome.org

Contact a Family
contact.org.uk

Orphanet
orpha.net

Cyngor

ar gefnogi teuluoedd y mae cyflyrau genetig, prin a heb ddiagnosis yn effeithio arnynt

Peidio â bod ofn dweud ‘Wn i ddim’

Nid yw’n bosibl gwybod am bob cyflwr genetig, prin a heb ddiagnosis. Mae teuluoedd yn deall hyn ac yn gwerthfawrogi gonestrwydd. Byddwch yn onest faint rydych chi’n ei wybod a dangos eich bod chi’n barod i ddysgu neu ofyn i eraill am help. Gall hyn helpu i gael teulu i ymddiried ynddoch chi a meithrin perthynas dda.

Gwrando

Mae teuluoedd yn aml yn dweud nad oes neb yn gwrando arnynt, neu fod eu pryderon yn cael eu diystyru. Y teulu fel arfer yw’r arbenigwr ar gyflwr eu plentyn ac yn y sefyllfa orau i ddweud sut mae’r cyflwr yn effeithio ar y plentyn a beth yw ei anghenion.

Cyfeirio

Gall fod yn anodd i deuluoedd ddod o hyd i wybodaeth a chymorth sy’n ddibynadwy. Ble’n bosib, helpwch deuluoedd i fynd at y cymorth priodol. Gall Genetic Alliance UK helpu i chwilio am grwpiau cymorth perthnasol a datblygwyd yr Adnoddau Prin i helpu teuluoedd gael gafael ar wasanaethau gofal a chymorth yng Nghymru.

Top Tips

for supporting families affected by genetic, rare and undiagnosed genetic conditions

Don’t be afraid to say ‘I don’t know’

It is not possible to know about every genetic, rare and undiagnosed condition. Families understand this and value honesty. Be honest about your level of knowledge and demonstrate that you are prepared to learn or ask others for help. This can help to build trust and a positive relationship with a family.

Listen

Families often report that they are not listened to or that their concerns are dismissed. Families are typically the expert in their child’s condition and they are best placed to communicate how the condition affects their child and what their needs are.

Signpost

It can be difficult for families to find reliable information and support. Wherever possible, assist families to access appropriate support. Genetic Alliance UK can help find relevant support groups and the Rare Resources Toolkit has been developed to help families to find care and support services in Wales.

Siarad yn ystyriol

I lawer o deuluoedd, mae delio gydag gweithwyr iechyd a gofal cymdeithasol proffesiynol yn gallu bod yn brofiad go frawychus. Gallwch helpu i feithrin perthynas dda efo teuluoedd drwy siarad yn ystyriol; cyflwyno eich hun ac egluro eich rôl yng ngofal y plentyn, osgoi defnyddio jargon ac ystyried defnyddio cymhorthion (fel fideos ar-lein) i ddisgrifio pethau cymhleth. Mae apwyntiadau yn gallu bod yn straen i deuluoedd, felly mae’n bwysig dangos empathi a dealltwriaeth.

Cydlynu gofal

Bydd angen gofal cymhleth ar blant sydd â chyflyrau genetig, prin neu heb ddiagnosis gan wahanol weithwyr iechyd proffesiynol. Er lles y plentyn a’r rheiny sydd yn gofalu amdano, mae angen sicrhau bod gofal yn cael ei gydlynu’n iawn. Ble bynnag bosib, ceisiwch gydlynu efo darparwyr gofal eraill a helpu teuluoedd i gael cydlynydd gofal penodedig.

Ystyried y teulu

all plentyn sydd â chyflwr genetig, prin neu heb ddiagnosis effeithio’n sylweddol ar fywydau aelodau eraill o’r teulu. Meddyliwch am anghenion rhieni sy’n ofalwyr a brodyr a chwiorydd pan fyddwch chi’n gweithio gyda’r teulu – holwch sut maent yn ymdopi neu a oes angen unrhyw gymorth arnynt. Ble’n briodol, cyfeiriwch aelodau’r teulu at ffynonellau cymorth ymarferol, emosiynol ac ariannol. Mae’r Pecyn Adnoddau Prin yn rhoi gwybodaeth i rieni sy’n ofalwyr am wasanaethau cymorth sydd ar gael yng Nghymru.

Communicate considerately

For many families, dealing with health and social care professionals can be a daunting experience. Help to build a positive relationship with families by communicating considerately; introduce yourself and explain your role in the child’s care, avoid using jargon and consider using aids (such as online videos) to describe complicated things. Families can find appointments stressful, it is important to show empathy and understanding.

Coordinate care

Many children with a genetic, rare or undiagnosed condition require complex care from a range of different health professionals. It is in the best interests of the child, and those involved in their care, to ensure care is properly coordinated. Wherever possible, coordinate with other care providers and assist families in obtaining a dedicated care coordinator.

Consider the family

Having a child with a genetic, rare or undiagnosed condition can significantly affect the lives of other members of the family. Consider the needs of parent carers and siblings in your interactions with the family – ask how they are coping or if there is any support that they need. Where appropriate, signpost family members to sources of practical, emotional and financial support. The Rare Resources Toolkit provides information for parent carers on support services available in Wales.

Eich **Nodiadau**

Your **Notes**


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