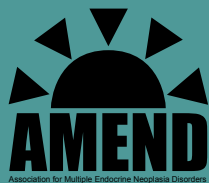




# Looking after yourself

**A guide for partners and family members**

written by Kym Winter, AMEND lead counsellor



## **MEN SUPPORT**

**Tel: 01892 516076 / 841032**

**Email: [info@amend.org.uk](mailto:info@amend.org.uk)**

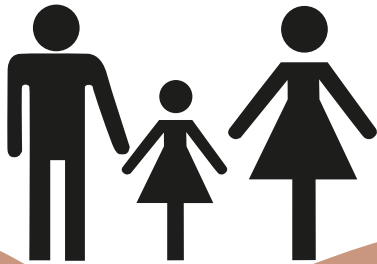
**[www.amend.org.uk](http://www.amend.org.uk)**

Registered Charitable  
Incorporated Organisation  
no. 1153890

**AMEND Membership, resources  
and services are FREE**

## Introduction

Giving support to someone with a rare endocrine disease can give you both rewards and challenges. How you feel about giving support will depend on how much this affects you at any point in time. While we use the term carer in this booklet, you may prefer to think of yourself as a supporter, advocate, or simply as a partner. The term you use is up to you and the life that you live. If you have a long-term partner or spouse, making the choice with them can lead to a helpful discussion about this aspect of your relationship. With inherited conditions, a carer often gives support to both a partner and also to one or more children. You may also have to care for an affected parent too. As well as being a carer, you might also be holding down a job, and managing a home. There may well be times when dealing with all these demands might feel very stressful. This booklet is to help support you in living with a rare endocrine disease too.



## Dealing with diagnosis

When someone in your family gets a diagnosis of a rare endocrine disease there may be a range of emotions. Relief is common if they have been unwell for some time without knowing the cause. It is also very common to feel sad, frightened, angry and anxious. Sometimes a diagnosis is unexpected and is a complete shock. In inherited rare endocrine diseases, a diagnosis can affect decisions about your future life, such as starting a family. A diagnosis can lead to all sorts of changes to your relationships. It can take time to process these. Some people experience positive changes, with couples and families saying that it helped to bring them closer. Others say that it has caused tension and arguments. This difference is often down to the different ways that people deal with things. Some people want to talk through things more than others. Most people say that the impact on their relationship is a mixture of good and bad over time. Our leaflet 'Dealing with Diagnosis' is relevant for carers, as well as for patients.





## Relationships

### With your partner

Couples often talk about how the disease has helped them to understand each other better, but it can cause a lot of stress in a relationship too. You may feel that you are left 'holding the fort' at home if your partner is ill, tired, or having surgery or other treatment. It is very normal to feel resentful, angry and tired yourself at times like this. If you and your partner are having relationship problems, it is helpful to bear in mind that you both carry the added stress of living with a long-term condition. Sometimes your normal roles might change. For instance, you may need to

work instead of your partner or while your partner is ill. Or perhaps you have to work and take care of the chores at home too.

Sex can also become a source of conflict. This may happen if your partner is too tired or ill for sex when you want to be close. Sometimes the disease can cause changes in your partners body, and how they look or feel about themselves. This can impact on how you feel about being physically intimate with them too. Just cuddling, or doing things together that you both enjoy can help you feel close in other ways.

Talking about any problems or worries that arise, and finding

support for you as a couple can be very important to help you both to deal with the affects of the disease on your relationship. You may find this support from good friends who you can be open with, family members who can offer practical support, and professional help such as AMEND's support groups or counselling (helpful resources are found at the end of this booklet). Couples' counselling can also be a very helpful way of understanding each other better, and finding new ways to deal with difficulties. We have listed some organisations to contact at the end of this booklet.

*'We kept rowing about stupid things. I was really worried about my wife, but couldn't tell anyone as I was trying to be 'strong'. She had a real go at me one day and said she was fed up with me acting like I was fine when I wasn't. We had a good cry, and I'm trying hard not to shut her out as much now.'*  
John, 42

### With your children

If you have a child with a rare endocrine disease, supporting them to live well with it will be an ongoing project. It can be upsetting and an emotional challenge taking your child for regular blood tests and treatments. It can also be very time consuming. Managing your child's anxiety as well as your own can be demanding. Worries about their on-going and future health can also have a negative impact on you. If you are having trouble talking to your children about their condition, AMEND's booklet on 'Talking to children and young people about MEN' will help as it applies to other diseases too. If you have another child who doesn't have the condition, you might feel guilty that you spend more time with the child who has. Children can also feel upset, in particular when they see their sibling taking time off school and getting treats while they are left at school. You could try including your unaffected child in hospital trips so that they don't feel left out. You could also try arranging special time with them alone too.

Supporting a teenager with a rare endocrine disease can bring new challenges. Problems often occur as they become more independent. Often this comes from dealing with their own hospital visits and medicines. They may also want you to be involved at some times, and not others. Talking to other parents at AMEND's Information Days and online forums can be good source of ideas and support.

### *With your extended family*

Some families become closer as a result of a diagnosis. For others it can open old wounds or add to tensions that already exist. This can feel very painful to deal with. Letting other people know what you find helpful (or not) can help other people to respond in such a way that means things improve with time.

*Remember: you can't control how other people behave, but you can decide how you want to respond. Good communication is key, as well as being gentle with each other when someone gets it wrong.*

## *Managing Practicalities*

### *Managing Uncertainty*

Part of living with a rare endocrine disease is bearing the uncertainty of the condition. There may be long periods of time when your partner is well, but other times when social plans, events or holidays have to be postponed, cancelled or delayed. Talk to your partner about going to some events alone. You can then benefit from the support, and your partner can rest without feeling guilty. There may be other things you can do together instead. Our booklet 'Living with Uncertainty' also contains ideas and suggestions that can apply to both patients and carers.



### *Impact on finances*

The impact of the disease may mean that you or your partner needs to stop work, or reduce your hours. Less income may mean that you can no longer afford to spend money, including on socialising and holidays. This can be upsetting at a time when you might feel that you have enough to deal with. You may be eligible to receive support in the form of benefits. The benefits system can be very complex, so talking to a financial advisor or one of the organisations we list at the end can be helpful.

### *Managing your work*

It is up to you whether or not you tell your employer that you are caring for a family member with a complex life-long condition. Laws are in place to prevent your employer from discriminating against you for being a carer. It is hoped that by sharing news of the diagnosis with your employer, they can be supportive. This may mean giving you time off for hospital appointments, a period of leave, or help in managing your workload

if things are very stressful at home. You may be able to ask for your hours of work to be reduced either permanently or for a certain length of time. It is worth checking if your employer has HR Policies on flexible working and on supporting carers.

Carers often say that to carry on working helps them to retain their identity from before they became a carer. They enjoy support from colleagues, and overall feel it is good for them.

It's important to make the right decision for your own situation. AMEND's booklet called 'Employment & Returning to Work' may be helpful. Although it was written for patients, it also contains information that is relevant for carers.

### *Managing medical appointments*

Keeping track of medical histories, hospital appointments and medicines can often make you feel like a secretary to your partner or child! It is very helpful to use a large file for letters and paperwork, and a notebook for keep track of

questions and answers during hospital appointments. If you have MEN, AMEND has free MEN Passports to help with this process. During appointments, many patients rely heavily on their partners to help remember what was talked about. This is most useful when the news is complex, upsetting or difficult. You might be happy to take on this responsibility, but ensure that you make time to talk through your own thoughts and feelings too, even if you do this later on.

AMEND's booklet called 'Working with your Medical Team' also contains further helpful advice.



## Looking after yourself

### Dealing with difficult feelings

Giving support to one or more family members with a rare endocrine disease is often emotionally and practically demanding. It is important not to let your own physical or emotional health needs slip down the queue. Having difficult feelings about the situation is not unusual. We may also take them out on the people we are closest to, and then feel bad about it. It is important not to be too hard on yourself, but rather to accept that you might at times feel:

- Resentful – about how the condition impacts on your life and relationships
- Fearful about the future
- Tired/exhausted
- Anxious or panicky
- Low, depressed or tearful
- Guilty – about not wanting to support your loved one sometimes
- Angry – about how this condition has affected your life
- Jealous – of couples or

families who don't have to live with the condition

- Lonely – as being a carer can be very overlooked and misunderstood

These feelings are all very normal. They can be easier to bear if you try and share them with someone you trust. This might be a family member, a friend, a spiritual or religious leader, or a professional counsellor. Families and couples have also told us that learning to accept and live with the condition can have positive impacts. These include better communication, making better choices, and making the most out of life.

*'It's brought us closer really. Stuff that would have stressed us out before doesn't matter now. We appreciate what we do have, like - in our life - and as a couple right now, much more.'*

*Sam and Niamh (30's)*

Below are some practical ways to look after yourself and your needs. Finding a balance between being a carer and taking time off from caring is important. Not every approach here will be right

for everyone, but it's important to find ones that are helpful for you.

### Engaging with the condition:

Patient Groups like AMEND can provide a number of ways to engage:

- Local Support groups – for meeting others in similar situations who are local to you
- Online Support – in the form of private Facebook groups
- Websites – containing plenty of information, videos and other resources. Use only trusted resources like AMEND to avoid incorrect and often frightening information
- Patient Information Events – such as AMEND's Annual Patient Information Day where you can network with other carers and learn from expert speakers
- Carers Support groups – these are often run by local community groups, or hospitals. Your GP may have details of ones near you.

Contact AMEND for further information on any of the above.



## Taking Time Out:

- Maintain your own interests and hobbies such as a sport, art/photography, music, or craft
- Don't neglect your own needs – take time to exercise, eat well and see the GP for any of your own health issues
- Take little moments of self-care everyday such as taking a nice bath, yoga, going for a walk, a 'special' cup of tea, buying a magazine, writing a journal, listening to music, watching a film/DVD you like
- Learn a skill like Mindfulness – an introduction is available via AMEND's website
- Plan for days off now and again to recharge, such as a day out with a friend, or a day just to yourself
- Remind yourself that you are not 'superman/woman'
- Talk to a counsellor if you feel you are not coping as well as you would like

Carers often want to be strong for those they support. Therefore it might feel difficult

to accept if you start to feel overwhelmed, or that you are not coping, feel trapped, or are even feeling suicidal. It is important that you have support too. If you start to feel like this, you should talk to your GP, the AMEND Counselling Service, or another professional counsellor.

*My husband has been quite stable with his MEN since surgery a few years ago. Our son had surgery last year too, and our daughter is on a 'watch and wait.' I couldn't understand why I kept getting upset all the time, as things are okay really. My friend has been really supportive, and suggested I might need to start taking more time for myself. I've now joined a choir, and making time 'just for me' has really helped.' Ella, 54*

## Being a Young Carer

If you are a young person caring for someone with a rare endocrine disease, you may have many different concerns. You may have questions about what will happen long-term, or have worries about them and their health right now. It is very common to have a mixture of feelings about a close family member having a health condition. Try to discuss any concerns you have with your parent, or if that doesn't feel possible, talk to someone else you trust, such as another family member, a friend's parent, or a teacher. The important thing is not to feel on your own with any worries you have, and to be able to get on with your own life, such as school and with friends. AMEND is there to support you too, and there are also other organisations for 'carers' listed at the end of this booklet that support young carers too.

### Worrying about the worst

Everyone is affected by his or her condition differently. Some people live for a long time with their condition, but others may not



and this can be very upsetting. It can help to remember that new treatments for the disease or to control symptoms become available from time to time. If you have worries about your partner or child dying early, it is important to share these with someone else, as it is a big emotional weight to carry alone. This might be your partner themselves, but if that feels too difficult, talking to someone you trust or to a professional counsellor. There are lots of organisations available to help prepare and support you through bereavement. It is important to know that you will not have to manage alone.



## Useful Resources

**Carers UK** [www.carersuk.org](http://www.carersuk.org) A national charity providing information and support for carers (0808 808 7777)

**The Carers Trust** [www.carers.org.uk](http://www.carers.org.uk) is another charity that supports carers, including Young Carers, and an online chat forum. They also have regional groups and partners.

**Young Carers** [www.youngcarers.net](http://www.youngcarers.net) is a new organisation that also operates across Twitter, Facebook and Instagram

**NHS** [www.NHS.org](http://www.NHS.org) has advice and information for carers. Your local council may also run support services or groups for carers in your area. Your GP or library may have details.

**Mindfulness** is a specialist technique that can be very helpful in dealing with uncertainty and stress. Both [www.mindful.org](http://www.mindful.org) and [www.headspace.com](http://www.headspace.com) are good places to find out more. AMEND has free Mindfulness resources via its website at [www.amend.org.uk](http://www.amend.org.uk)

**AMEND Local Support Groups** – meet 2-3 times per year in a variety of local areas in the UK. Visit [www.amend.org.uk](http://www.amend.org.uk) for more information

**AMEND Facebook Groups** – for AMEND members to share news, information and support in closed groups for your particular condition. Join AMEND at [www.amend.org.uk](http://www.amend.org.uk)

**NET Patient Foundation** [www.netpatientfoundation.org](http://www.netpatientfoundation.org) – information, advice and a nursing helpline for support in dealing with neuroendocrine cancers

**Samaritans** Tel: 116 123 (or [jo@samaritans](mailto:jo@samaritans)) provide confidential support for those in emotional distress 24 hours a day, not just if you are suicidal

## Benefits/financial advice

**Citizens Advice Bureau** [www.citizensadvice.org.uk](http://www.citizensadvice.org.uk) is a charitable network across the UK providing free, confidential information and advice for money, legal, consumer and other problems. Check your local area for a branch.

**Turn2us** [www.turn2us.org.uk](http://www.turn2us.org.uk) is a national charity that helps people in financial hardship to gain access to welfare benefits, charitable grants and support services

**MacMillan** [www.macmillan.org.uk](http://www.macmillan.org.uk) Tel: 0808 808 0000 provide a range of support for practical, emotional and financial problems, including a helpline 7 days a week 8am-8pm

## Counselling and Relationship Advice

**Relate** [www.relate.org.uk](http://www.relate.org.uk) for advice on relationships generally, and also for a list of specialist couples counsellors near you

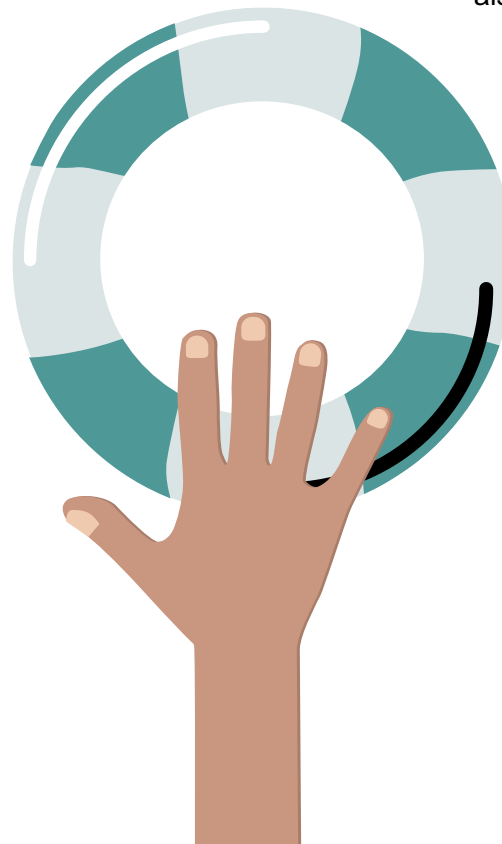
**College of Sexual and Relationship Therapists (COSRT)** [www.cosrt.org.uk](http://www.cosrt.org.uk) also contains general relationship advice, and also a list of registered therapist near you

**British Association for Counselling** [www.bacp.co.uk](http://www.bacp.co.uk) for both individual and couples counsellors in a particular locality

**AMEND Counselling Service** a free counselling service by phone or skype for AMEND members. Contact details are shared upon joining. Join AMEND at [www.amend.org.uk](http://www.amend.org.uk)

**Remember that your local GP/hospital might provide access to free counselling or support locally, so do ask.**

*With thanks to patients and carers who have generously given permission for their experiences to be shared in producing this information. All identifying features have been changed.*



## *About AMEND*

AMEND is a Charitable Incorporated Organisation registered in England and Wales (number 1153890). It provides support and information services to families affected by multiple endocrine neoplasia and related endocrine conditions. AMEND hosts regular free patient information events every year and has a free counselling service for members. We rely entirely upon donations in order to provide all our resources and services for free.

If you have found this resource useful, please visit our website for more information on AMEND or to make a donation: [www.amend.org.uk](http://www.amend.org.uk)

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## *Notes*