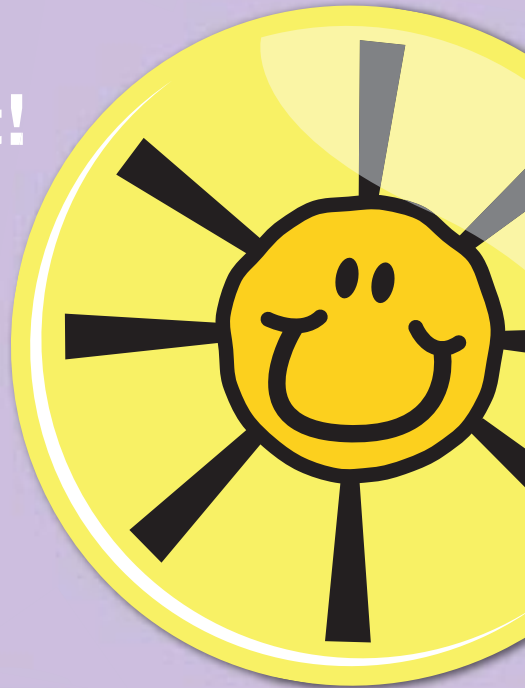




Say 'I'm Fine' ...and Mean It!

If you look after someone,
who is looking after you?



"A cheerful, easy-to-digest
book with lots of good
suggestions" – *A Carer*

Say 'I'm Fine'...and Mean It!

Mental Health and Emotional Wellbeing for Carers

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It gives us great pleasure to publish this book at an important time for Carers in Wales. With 1 in 8 adults providing unpaid care to a family member or friend many of us have direct experience of caring, of being cared for, or know someone who is doing this. Carers undertake essential tasks for family and friends, and therefore for the community in general, but much of this work goes unnoticed.

Every day Carers provide a vital role in the support, care and treatment of people with long-term and/or multiple conditions, disabilities, illnesses, dementia, and substance misuse issues.

The commitment to their task can mean that they experience financial, physical and emotional difficulty and potential hardship. When a Carer's health deteriorates through lack of support, it is much more likely that the person they care for will be admitted to hospital. Supporting and enabling Carers to establish and maintain a healthy lifestyle to look after their own health and wellbeing to make sure that the person they care for is able to remain in their home whilst being safely and appropriately supported.

We view Carers as partners in the provision of care, being involved in the decisions which affect them, and not passive recipients of support services. Through the provision of quality information, such as this booklet, we want Carers to have a joint voice in negotiating and planning the high-quality, flexible support they need to manage their caring responsibilities with confidence, keep them in good health, and enable them to enjoy a life outside of their caring role.

Where areas of good practice exist we will mainstream them throughout the partner organisations. One example is the Investors in Carers scheme which has seen that most GP surgeries in the Hywel Dda region receive a bronze award, with other settings such as Community Pharmacies, Mental Health areas, Libraries, Community Hospitals, LA departments, and 3rd sector organisations also engaging with the scheme.

These settings have successfully proved their ongoing commitment to Carers and demonstrated that they are taking proactive measures to support Carers in their areas. This includes identifying 'hidden' Carers; increasing communication with professionals and voluntary organisations; targeted health checks for Carers; and by showing evidence of Carer feedback on services. The good practice developed through this scheme will be developed further for settings to aim for their silver and gold levels to further support Carers in their communities.

We want to hear about Carers' experiences of our services, whether good or bad and we will develop ways to ensure that Carers' views and concerns are integral to the planning of care and services.

Caring for another - whether it be for a few hours a week or all of the time it can be a rollercoaster of emotional highs and lows. It is really important to take a step back at times and consider your own health and wellbeing as a priority. We hope that this booklet, will now reach Carers like you across the three counties and that you will find it of value. It can help you to recognise when it is time to seek help, guide you to sources of support in your local area, and provide some assurance that you are not alone. We trust you will take heart from reading it and will use the information in it to keep yourself, and the person you care for, living well.



West Wales Care Partnership
www.wwcp.org.uk



About this booklet

Whether you have been a carer for a while, or are new to caring, life can feel pretty tough. The good news is that there is a lot of information and support available to you.

This booklet is designed to be a quick read which, whilst we hope will be useful in its own right, will point you in the right direction. Anything we mention here is listed in the '**For More Help**' section on pages **34-48**. Just look up the number.

When we set out to write this booklet we wanted it to appeal to carers and to those who have not yet recognised that they might be a 'carer'. We felt there was a need for a short, practical booklet that focuses on the important subject of health and wellbeing. We hope it fills this gap and that, now you've picked it up, you find it a source of support and strength.

A Carer recently obtained the book at a Carers Rights Day event and said:

"I noted from the publication you gave me "Say I'm Fine - and Mean It" there were some interesting books I would like to read. That publication in itself is priceless. How I identified with every single page. From now on that book is going in my handbag. It is a fabulous tool in itself".

1 Introduction

Who is a carer?

You might not think of yourself as a ‘carer’. You’re simply looking after your parent, partner, child, friend or neighbour and doing what anyone else would do in the same situation. ‘Carer’ is a description adopted by carers more than 30 years ago to explain what they do beyond the role of a traditional relationship and to get recognition for it. It describes someone carrying out extra tasks without payment for someone who cannot do them for themselves. So maybe you are a carer after all?

There are many different kinds of caring. You might be looking after someone because they are elderly, ill, have a mental health problem or a physical disability, or are dependent on drink or drugs. The caring role can stretch from doing a bit of shopping or sitting in with an elderly neighbour, to looking after the needs of a parent or spouse full-time. This might include tasks such as help with getting up and going to bed, dressing, washing, using the toilet, cooking and cleaning. If the person can’t manage without you then you are likely to be a carer.

This booklet is for anyone who recognises themselves in this description, including young people. If your parent or another member of your family can’t cope on their own, and you’re helping, then you are a carer too. The information in this booklet, along with the special section at the back, is for you.

The word ‘carer’ is useful shorthand, but can’t adequately reflect the ongoing relationship we have with the person we now ‘care for’. For the most part our loved ones continue to contribute to the relationship – there’s still a give-and-take. However, if you are able to acknowledge your extra identity as a carer it can mean you have access to additional support and finance.



Recognising you're a carer also matters because, once you do, you can take a step back and think about yourself as well.

The impact on your life

Maybe the caring role has crept up on you, until gradually you realise the person you care for is dependent on you for many things. Or maybe it came suddenly due to illness or accident. Maybe you stepped into the breach, and you're still there. If you have only recently started caring it may feel like your life has been turned completely upside-down. If you have been doing it for longer it may not even feel like your life any more. You may have had to give up work, or work less, or stop doing any number of things that were yours – just for you – because there isn't the time or opportunity or money.

How are you feeling?

Caring for someone can be very rewarding. And, for all kinds of reasons, it can be one of the most difficult jobs in the world. Caring is physically and emotionally demanding. If you're fitting in caring with other responsibilities, or you're working, or are looking after someone full-time, it is exhausting. Then there is the emotional strain of the change in your situation and that of your relationship with the person you are now caring for.

You may struggle with ‘the system’ – for money, information and support. You may feel alone and that no one can possibly know what you’re going through. This booklet talks about some of those feelings, points you to some ways of getting help, and gives you practical ideas for looking after yourself.

“Caring is more than just a job. It’s more than going for the prescriptions; it’s more than doing the shopping or helping the person you care for dress. It’s a commitment to someone you love. It’s supporting their emotional and physical needs and helping them retain their pride and dignity.”

A Carer

2. Caring and Your Health

This section describes in more detail the impact caring can have on you and how you might be feeling. If you recognise yourself here, go to **‘What you can do about it’** to find ways to help yourself.

How caring affects your mental and physical health

Caring takes a toll on your physical health as well as on your ability to cope and the way you feel. These two aspects of health are related, as we will see.

“People use the term ‘stress’ to describe the feeling they have when it all seems too much, when they are overloaded and don’t feel that they are able to meet all the demands placed on them.” (From the Samaritans website)

Sound familiar? Stress is our response to pressure from the outside world.



We all need some impetus to make us get up in the morning, but if the demands become too much for us we may feel tense, irritable, and unable to concentrate, feel overwhelmed, have physical symptoms like headaches or have difficulty sleeping. We may find we are drinking more alcohol, eating for comfort or smoking more. If stress goes on for a long time – which is likely if you are caring – it has a damaging effect on your mind and body. Your immune system is less able to fight infections and you become less able to cope. Your mental and emotional health is a measure of how well you are able to manage stress, survive difficulties and enjoy life. This positive sense of wellbeing can be increased, and you can become more resilient, by looking after yourself and learning coping strategies.

For more information see Section 4: 'Looking After Yourself' later in this booklet.

Stress increases if you have the feeling you have no control over your life. When you started caring you may have felt you had no choice about taking it on. You have made choices about what is important to you – love, duty, responsibility – but you now have some experience about what else is involved. So, it may be worth stopping to consider whether you want to make a change in the way you fulfil your caring role. You do have the choice to stop if it gets too much; it doesn't mean that you don't care **(1)**.

What might you be experiencing?

Whatever motivations you had for taking on the caring role you are likely to be dealing with some difficult feelings alongside the daily problem-solving. Becoming a carer can seem like a series of losses or bereavements. The loss of the life and person you thought you were, of the relationship you hoped to have, the loss of work and the status and identity it gave you, your privacy, interests, social life...You may feel anger, sadness or resentment about these changes or losses.

Many carers feel guilty, mainly that they are not doing enough for the person they care for, that they are not up to the job or, worse, that they have done or thought something unforgivable. You're in a situation which is very likely to make you feel this way.

You may feel resentful if the person you care for doesn't seem to appreciate what you do for them. And then guilty because it's them who is suffering, not you. Or you may resent people you think should be helping out more, be they family or professionals (27).

It's possible you feel angry – with the system, with the fact you've ended up here in this situation – and it may lead to the questioning of a long-held faith. If the person you're caring for is suffering and you feel powerless to help, that can add to your anger. Life can seem very unfair.

A changing relationship

It can be difficult to deal with the change in your relationship with the person you now care for. The change in them – physical or mental – affects how you interact with them and this can be another loss.

Isolation

Depression

Where you used to call on your mother for help, now you find that she is dependent on you, even for the most intimate kinds of care. Or the equal relationship you once had with your partner can now feel like one-way traffic. If you are looking after a disabled child, the normal transition children take to independence may be delayed or trickier.

One change may be in the physical nature of our relationship with our partner. Sex is one way we use to express our feelings. If these change, or we are physically tired, then our need or desire for sex may change too. There may be difficulties if our partner still wants to have sex, or if they no longer want to, but we do. Talking about it with your partner can help, or with a counsellor if it becomes difficult **(28, 38)**.

But, however different our relationship becomes, it can be helpful to recognise the many ways in which we still support each other and enrich each others' lives. Appreciating the other person by noticing the things you like about them or the positive things they do can have a wonderful effect. If you do it sincerely, and tell them, it deepens your relationship and often you will find it is returned.

Loneliness and isolation

You may not have the same contacts with people that you used to, or you may find that you are so busy it's hard to connect with people. There may also be a sense that people don't really understand your situation and that you are the only one.

This can make you feel isolated and lonely.

(See the section 'Who can help'.)

Depression

If these feelings continue you may end up losing all enjoyment of life and feeling depressed. People who are depressed often feel guilty or worthless, lose their appetite, have difficulty sleeping or sleep more than usual, become anxious or tired or find it difficult to concentrate. It is common to experience this from time to time, but when it lasts longer than a few weeks or starts to interfere with our daily life, that's a sign we need to get help.

Depression is a common reaction and can be treated through self-help combined with professional help **(5)**. (See the section **'Looking After Yourself'**.)

If you start to feel hopeless about your situation you may have thoughts of escape. It's relatively common to have thoughts about harming yourself or the person you care for. If you recognise this, use it as a red warning-light and get help from your GP or someone else now **(15, 22, 23, 24)**.

Handling difficult feelings

Most of us handle these difficult feelings by ignoring them. This could be because we are afraid they will overwhelm us; or we feel we have no right to feel this way; or that if we were a different (better) person we wouldn't feel like this.

Take a deep breath. What you're feeling now is normal and thousands of other carers have been through something similar. Now breathe out...and read on. Whatever it is you are feeling, the first step is to accept that this is how you are feeling right now. Name it, sit down quietly and just feel it for a while.

The bigger picture

Carers are a hidden workforce. There are 6 million in the UK which means there are many people doing the same as you every day, making a huge contribution to society. But this dedication and work is not adequately recognised – through money or status. Looking after people, seen as women's role, is devalued generally by society. Not only that, but a lack of understanding about disability, mental illness and dependence on alcohol and drugs results in fear, stigma and a lack of sympathy. This can include the people who care for those who suffer in this way. All of this adds up to a considerable cloak of invisibility.

One useful idea is to think about disability, not as an individual problem, but as a social one. Because society does not adequately consider and include people with an impairment or chronic illness, they face many barriers in daily life. And because you are looking after someone whose needs are not taken into account, you are disabled along with them. So you both need support. Standing up for what you need, getting your voice heard, helps you and other carers, both now and in the future **(18, 20)**.

Money

Money, or rather lack of it, can be a huge stress for carers. At a time when your income has (probably) gone down, your expenses have gone up. The first thing is to make sure you claim everything you are entitled to **(1, 10, 42)**. The government agencies will help you do this. Then your next priority is to make the money you have go as far as possible.

Make sure you are in control of your finances and make savings where you can **(48)**. Be positive by making a list of all the things you can do which are free or don't cost much. Carers can often get discounts on cinema and other trips out – it is always worth asking. If you are anxious about your finances or the impact of caring on your job security, or you fall into debt, talk to someone **(1, 45)**.

What you can do about it

You might recognise yourself and the way you feel in one or more of these descriptions. The next sections suggest some ways of managing these feelings and of taking positive steps that will relieve some of the pressure and give you more ways of coping. We said that stress increases if you feel you have no control or choice about what happens. So what do you have control over? You can't change the situation, but you can change the way you think about it **(33)**. In fact, if you want to stay sane, it's vital that you do. Developing compassion for ourselves and others can help as can learning a technique such as mindfulness. Mindfulness is a way of paying attention to the present moment. It can help create some space between us and the rush of thoughts and feelings that often threaten to overwhelm us **(32)**.

There is enormous value in being able to step outside our situation and look at it gently from a different perspective. Being able to simply acknowledge the way things are without judgement can help us change ourselves even if we can't change the situation. Be alert to finding unexpected rewards from caring – discovering inner strengths you didn't know you had, a deepening emotional bond with the person you care for or perhaps a slowly emerging sense of satisfaction.

You can reduce stress by knowing your own limits. Do one thing at a time. Lower your expectations – be realistic about what you can achieve each day and celebrate your successes. You might decide to adjust your standards. Who cares if the vacuum cleaning only gets done once a week? Housework or a 15 minute nap? No contest. Or are there friends, family or a local organisation that could help out? **(10,11,12,13)**

There are some things that might help you negotiate those moments when you think you're going to snap:

- **Slow your breathing**
- **Leave the room and review your feelings**
- **Take some exercise**
- **Try not to use drink or drugs as a way to absent yourself.**

Your body stores up tension if you are stressed. It can be very helpful to learn how to relax your body. You can do this through relaxation exercises **(7, 32)**.

One writer of a book for carers suggests it can be helpful to approach your caring role as a professional job, particularly when doing the really intimate things like washing and toileting. This can no doubt be valuable in a very difficult situation, but if we approach the whole task in this way we are in danger of losing our vital connection with the person we care for. Somehow we have to carry on seeing and connecting with the person we know behind the illness, disability or frailty and stay open to the give-and-take that still exists in our relationship with them.

We humans try to avoid suffering, and when it is the people closest to us who are suffering, it is hard to bear. How can we do this with an open heart, yet still look after ourselves? Somehow we need to balance our own needs with those of the person we care for.

In the next two sections we look at the help available and the ways you can look after your health and wellbeing to make sure you get what you need.

3. Who Can Help?

Asking for help

One thing that can really help you with these difficult feelings is to get some support – practical or emotional. You are not on your own, though it may feel like it. There are professionals and others who can – and want to – help. It might not always be easy to find the right key to unlock the door, but it pays to be persistent.

Remember, if you can no longer cope, they will have to pick up the pieces. It's not always easy to ask though. You may not know where to go or feel you don't have the time to find out. Some carers fear losing control or being judged, or feel that they have failed in some way.

Try considering it a strength to be able to ask for help. You may feel that you don't need help at present. If so, just tuck this away for future reference. At different times you may feel desperate for information and at others totally overwhelmed by it. Again, keep this for when you need it.

The Professionals

It may be helpful to remember that professionals – those working in the paid caring professions – are often confronted with an ever-increasing workload and responsibilities, and many are not well paid. It can be frustrating, you may have to be persistent, but don't give up. The professionals are doing their best, they are there to help you as well as the person you care for and they want to be supportive. All professional organisations have a way for you to comment on your experience – use it.



If you reach the point at which you feel you are not being heard an advocacy organisation may be able to help. You have the right to have your views taken into account when an authority is considering how best to provide support for a disabled person.

Most importantly of all for your situation, carers who provide a 'substantial' amount of care on a regular basis are entitled to request a separate Carer's Needs Assessment **(1)**. Someone from Social Services will come and talk to you about the help you need as a carer.

Carers say that the assessment has been an opportunity to get information and to talk through the problems they are dealing with. Many have found it helpful to have their contribution recognised and to know they are sharing the responsibility with someone. So this is not the time to say "I'm fine". The professionals want to support you to continue caring because if you don't, most likely they will have to. This is an opportunity for you to get help, so be honest and open about your needs.

“While my initial reaction to having an assessment was somewhat apprehensive, it was carried out in complete privacy and confidentiality, and I found that reassuring. The assessment helped me to realise that I too had needs and if these needs were not met the stress could lead to me failing to provide proper care as a carer. Finally the assessment has given me the courage to request that my needs are adequately met.”

A carer

Ask your GP to record the fact that you are a carer in your medical record. All GPs have a Carers' Register. In Ceredigion the 'Investors in Carers' award scheme for GP practices supports them to help carers better **(9)**. There will be a Carer Information Board or folder in the waiting area.

They will be able to give you advice and information about the medical condition of the person you care for as well as about practical tasks like nursing at home. If your doctor knows you will be under pressure at times they will also be better able to support your own health. And the practice should be able to put you in contact with local services and sources of advice and support. There is a wide range of voluntary or third sector organisations in Ceredigion that provide emotional and practical support for carers **(10,11,12,13,14,15)**. It can help you feel more in control if you get organised. Keep a notebook of things to do, people you've spoken to and so on **(29)**. Have a plan for who to call and what to do in an emergency. Your GP practice and Health and Social Care practitioners will be able to help with this and you may find the 'Carers Guide to Planning for Emergencies' helpful **(1,5)**.



The person you care for

Good caring is not always doing everything for the person you care for. One of the most challenging aspects of caring is to allow the person to try to do as much as they can or want to for themselves. We all need some control over our lives. Continuing to make choices and decisions is important, even if it is the small things like what clothes to wear or what to eat. If you're not sure how much the person you care for can manage, your GP practice or specialist services such as Occupational Therapy, Re-ablement or Enablement should be able to advise **(1, 5)**.

Friends and family

If you have written off friends or family members because they haven't been involved so far, here's the time to have a rethink. They may feel unable to offer help because they don't want to suggest you can't cope. Or they may want to help but feel worried that their offer will become unlimited and they wouldn't want to let you down. But you don't want them to take over, just to help out now and again. So be specific about what it is you want them to do and how often. It could be cooking an extra couple of portions of an evening meal once a week so you don't have to. Or sitting with the person you care for a few hours every week so you can go to a class or take some exercise.

Making a rota for tasks that can be shared can be helpful. If you can get lots of people to each do something small, it can add up to a big difference to you. You get time to yourself, a precious commodity, and those around you, who care about you, feel they are contributing in some small but significant way.

Other carers

Obviously each carer and each situation is unique, but your shared experience puts you in an excellent position to help each other. A support group offers a space where you can share knowledge, practical information and how you feel about your experience. The best ones value and understand you beyond your caring role. You can meet other carers through local carer support groups or online through carer forums and chat rooms (12, 19).

4. Looking After Yourself

Looking after someone usually takes place over a substantial period of time so you need to pace yourself. If you collapse under the strain it provokes a crisis and others will have to step in. To avoid this you need to pay attention to your own needs. It may seem sometimes that your needs are in conflict with those of the person you care for, but remember that the impact of the disability or illness on your lives is one that you both share. It could be that you need to make time to spend with the person you care for which is pleasurable and fun. And then there may be some things that **you** need. Take some time to write down what those needs are. Do you need time for yourself, someone else to talk to, to get out in the fresh air, get more sleep...? (1) 'Carers Checklist'



Time for you

One of the main stresses of caring is not knowing when, and perhaps how, it will end. We can usually find the extra resources within ourselves to keep it all together to deal with some emergency or crisis, but when the situation continues, stress builds up and can lead to burnout. To continue long-term caring you need breaks to take a step back and to gather your energies.

Finding time for you

If you can, give yourself some space – at least 15 minutes – every day, for you. Creating your own special area at home can help. This could be a physical space which is yours where the understanding is that you will be undisturbed. You can use the time you set aside for cooking, having a bath, walking round the garden, listening to your favourite radio programme. If this isn't possible see if you can create the space in your mind. Quieten your mind, breathe slowly and evenly and relax your shoulders. Stop when you can throughout the day to notice the world around you and appreciate it. Take two minutes to go outside or to put on a favourite song and have a sing or dance **(32)**. At the end of each day, on your own or together, write down three things that have gone well.

“What is this life if, full of care, we have no time to stand and stare?” *W.H.Davies*

Respite or replacement care

This is a chunk of time away from your caring role. Impossible, you say. There are obstacles to getting respite care, but ask yourself first if they really are obstacles or whether you are putting them there. The objections carers raise are real – that the person they’re caring for won’t allow anyone else to be involved, that they won’t want to go away from home, that they don’t want social services involved, and so on. But these can and should be overcome. Some carers think that only they can do it. If it means you can carry on caring then surely the compromise is worth it?

Having a serious break is the only way to really recharge your batteries. And it’s much better to do it before you break down or face a crisis **(1, 17)**. When you take this time out have a good think about what you do with it. Do something for yourself rather than fill it with chores. Rest, invest the time wisely.

Talk to others

Start talking to anyone who will listen – other carers, friends, family, professionals and neighbours. Putting into words what is happening helps you deal with the difficult feelings and gain some perspective. To save your sanity you have to break down the isolation and connect with others. If you have access to the internet there are many new ways of keeping in touch such as Facebook, MSN and chat forums **(19)**.

If you are not coping, and feel your emotional health is suffering, your first port of call should be your GP. They may be able to refer you for help or prescribe a self-help book or medication **(7, 8)**.

If you really feel as if you are going under you may want to talk to a counsellor about your feelings.

Make sure you get one either through your GP, personal recommendation or via one of the national registers (5, 38). Be clear about what it is that you want help with. There are also helplines for emotional support (22, 23, 24, 26).

‘We have much more to offer than we may realise. All we have to do is ask “How can I help?” with an open heart, and then really listen.’

Ram Dass, Carer

Your health

Your mind and body are inextricably connected. Looking after your body will help you cope with the strain of caring, improve your mental health and remind you that you are as important as the person you care for (17,30). So you need to find time to keep any doctor’s or dentist’s appointments you have and you also need not to ignore any symptoms (5,30). Talk to your GP practice to see if they can make it easier for you to attend. If you are getting formal carer support do they know you are struggling? Can you use your friends and family? If you feel your health is deteriorating because of the extent of your caring role then it may be time to involve social care services for practical help (1). Looking after yourself means being alert to your own warning signs and doing something about it. Don’t wait for others to notice.

Keep active

It may be the last thing you feel like doing, but doing something physical, particularly in the fresh air, is proven to be one of the best things you can do for your mind and body. It will give you more energy, can help you sleep better and relieves stress.

If you can get to an exercise or dance class this will also take you out among other people and give you a legitimate break from caring. You may be eligible for referral to 'Exercise for Life' **(4)**. If not, build exercise into your daily routine – a brisk walk or some gardening – even five or ten minutes outside will improve your mood. You can do exercises or yoga at home with a DVD or book.

Eat well

Food has a big impact on our health and how we feel. Eating healthily will help prevent you getting ill. It can be tempting to go for convenient foods like cake and biscuits or to keep ourselves going on coffee. Unfortunately both have a short term effect boosting your energy but then leaving you feeling irritable and tired. A healthy diet will make sure you get all the vitamins and minerals you need and the energy which will sustain you through the day. Try to eat a variety of foods, including plenty of fruit and vegetables. This may be difficult to achieve when you are pushed for time, but see if you can change a couple of things to make a difference, adding extra vegetables to meals or swapping white bread for wholemeal. Cold snacks or soup can be as nutritious if you find three meals a day difficult **(35, 36)**.

Sleep

A good sleep can be the first thing to go when we are stressed. It's useful to know that it's not how long you sleep (the amount each person needs is different), but how well that matters. The quality of your sleep can have a significant impact on your mood, energy and ability to concentrate. Most of us have a dip in energy in the afternoon and a 15-20 minute nap can keep you alert. You don't have to feel guilty about this – it's an investment in your energy bank. If you are having trouble sleeping make sure you follow advice on sleep hygiene and try a relaxation technique **(32)**.

Alcohol, drugs, smoking – why they don't really help

Alcohol or drugs may seem to help us cope temporarily but consuming larger amounts over time can lead to dependence and serious health problems. Whilst alcohol can make us feel good for a few hours, drinking larger amounts regularly alters your brain chemistry increasing anxiety and your risk of depression. If you think you are becoming dependent on alcohol to manage your feelings or stress consult your GP or an organisation for support **(30, 36)**.

It is a widely held belief that smoking relieves stress. In fact, studies show that it actually increases stress, anxiety and sleep disorders. If you smoke you don't need us to tell you that giving up is one of the best things you can do for your health. Consider whether now might be the time to do this positive thing for yourself. It can take a few goes to give up completely, but help is available **(37)**.

What else you can do

Many people find benefit in activities that help them to relax such as meditation, yoga and massage. Complementary or alternative therapies can support your health in a holistic way **(39)**. There are many relaxation and breathing exercises you can download which help if you are anxious or tense **(32)**. Noticing your body, its posture and feelings of tension and consciously standing or sitting in a relaxed and alert way has a direct effect on your thinking and how you feel.

Music is a wonderful way to change your mood. Use your favourite songs or pieces to relax or get you moving. Keeping a pet can be therapeutic. Animals offer an emotional connection, reduce stress and feelings of isolation. You don't have to be serious all the time.

If something funny happens, celebrate it together. Remind yourself of what raises your spirits and what used to make you laugh. Seek these out and find new ways too. You might think we're joking but it's been shown laughter is good for your health.

“Always laugh when you can. It is cheap medicine”
Lord Byron

Mindfulness is an increasingly popular form of meditation-based practice:

‘Mindfulness helps people see their situation, thoughts and feelings in a non-judgmental way so they can stop themselves reacting impulsively. It gives them time and space to consider a new way of acting, to break a negative cycle of thinking and doing, and to feel more in control of their actions...Anyone can learn mindfulness. It’s simple, you can practice it anywhere, and its effects can be life-changing.’

(Mental Health Foundation)

Go to the **‘For More Help’** section for more information on how to learn mindfulness **(31)**.



Here's a top ten list of evidence-based ways to look after your mental health. Pick one to do today.

Ten Ways to Look After Your Mental Health

1. **Talk about your feelings**
2. **Keep active – do something physical, something you enjoy and can do regularly**
3. **Eat well – a diet that's good for your physical health is good for your mental health**
4. **Drink sensibly**
5. **Keep in touch with friends, family and those around you**
6. **Ask for help – you're not superhuman**
7. **Take a break – a few minutes can be enough to de-stress you**
8. **Do something you're good at, or try something new**
9. **Value yourself and others**
10. **Do something for others – a small act of kindness makes everyone feel good**

(based on work by the Mental Health Foundation)(32)

'The Ceredigion Recovery Book' has many more ideas for reconnecting with life and yourself.

5. Learning, training and work

Your role as a Carer

Finding information about the medical condition of the person you care for can really help you to cope. However rare the condition you're dealing with, there will be a support group or national organisation somewhere (30). These will usually provide helplines and factsheets, but may also provide help for carers too. Your GP has access to information on all conditions or there may be a specialist nurse you can talk to (6). 'Looking after Me' is a six-week course for those looking after someone with a long-term health condition which helps carers learn ways they can look after

their own health whilst caring for someone else **(6)**. You can get training in how to move and lift someone. Ceredigion County Council provides this course in conjunction with voluntary organisations. Other courses that support carers such as managing stress and assertiveness run from time to time, or you can hire a DVD **(1)**.

Keep up your interests

If you can, maintain some connection with the person you were before all this happened. Work not only helps financially but can give you an identity outside your caring role with the status, social interaction and value that brings. It can be worth juggling these two roles to hang onto this. If you are in work your employer is obliged by law to allow you flexibility to carry out your caring responsibilities if the person you are caring for is a relative or lives at the same address **(1)**. Try hard not to give up those activities, clubs or social events that you already have. They can be a huge support and are often a lifeline when caring comes to an end. You may still be working, or you may want to start doing some work – paid or voluntary. Try to find the time and see if you can set the money aside to continue something that is important to you or to learn something new.

There are a wide range of courses (including on-line) put on by the university, colleges, local authority and others. Some may be aimed at carers, others are for the wider community. Anything that will absorb you and which takes you out of your caring role and connects you to yourself is good **(16)**.

“When I wasn’t caring I would just slump in front of the television watching anything. I felt my life was going nowhere. But now I feel more alive. I have something else in my life and it’s mine. I’m just glad I discovered the OU.”

A carer studying with the Open University

6. Life Beyond Caring

Your caring role will change over time and sometime it will end. It could be that the person you care for recovers enough, or grows up enough in the case of a disabled child, to move into independence. If the person you care for moves into a residential or care home or, as a young carer, you are leaving home, then your caring responsibilities will change. It could be that your caring role ends with the death of the person you care for. If you are anxious about the future it can be helpful to sit down with someone and talk it over. There are practical things that can be put in place for end-of-life care such as an ‘advance directive’ (11, 16, 20).

Caring is such an intimate relationship. It can be difficult to separate after the death of the person you have been caring for. For a while you are likely to feel lost with conflicting feelings of sadness, guilt, and relief. The financial support you had, and the professionals who supported you both, will disappear. Grief hits everyone in different ways and you will need to adjust to life without that person and your caring responsibilities. Take your time (14, 19).

“For the remaining months of his life we were totally at peace and comfortable together. No more self-consciousness. No unfinished business...In a way this was my father’s final gift to me: the chance to see him as something more than my father; the chance to see the common identity of spirit we both shared.”

Ram Dass in ‘How can I help?’



7. Young Carers

A young carer is a young person who helps look after someone at home by doing jobs around the house, cooking, cleaning, helping someone get dressed or washed or giving them emotional support, talking and listening to them. This might be your mum or dad, your grandparent, or your brother or sister if they have a disability. You may not have thought about yourself as a carer because it's probably always been like this for you. Many children help out at home but a young carer is often responsible for someone in the family in a way most young people are not.

“The skills you gain from it, like being really patient and just being quite sensible, they're quite useful in a lot of other situations, not just your caring role”.

A young adult carer

When someone in your family has an illness or disability or problems with drink or drugs it can be very confusing **(32, 34)**. It's normal to have a lot of different feelings about it. You may like the feeling of responsibility and get satisfaction from doing something useful for your family. Or you may feel angry, sad or stressed. Talking to someone who will listen to you can help you with these feelings. Maybe there's someone you know or you can join a discussion forum for young carers **(21)**.

Young carers say that although there are many positive and rewarding aspects to caring, they can miss out on things like school, social life with friends and activities. If caring is affecting your schoolwork, your health or causes you other problems, your family might be able to get help. It's really important you don't try and manage on your own. You can ask Social Services for an assessment **(1)**. If you need help it's their job to make sure you get it. You might be worried that your family may be split up if you ask for help, but actually the opposite is true.

The Social Services want to keep you together and will do everything possible to support that. You didn't ask to be a young carer – it just happened to you. It's not your sole responsibility. Is there a friend or relative, a teacher, school nurse or counsellor, GP or social worker, you feel you could talk to? It can help to write down or draw how you're feeling first.

Your school should have someone called a 'Carers Lead' who takes a particular interest in making sure young people get help with caring. Within Ceredigion there is a service especially for children and young people who provide care for someone **(2)**. There is also a 'Children and Young People's Information Service' **(3)** who can put you in touch with all sorts of help including linking up with other children and young people in a similar situation to yourself. Whatever your situation, take that first step and talk to someone about it **(1, 2, 19, 21, 22, 25)**.



Finally...

This booklet is a starting point. There is help available to share the responsibility you've taken on. It's up to you now to make the first move, to pick up the phone or get on the internet to reach out and connect with that help. It takes courage, but you are up to it. It's not easy, but things do change. Above all, don't lose sight of yourself.

“No matter what age you are, or what your circumstances might be, you are special, and you still have something unique to offer. Your life, because of who you are, has meaning.”

Barbara de Angelis, author of 'How did I get here?'

For More Help...

The following list links to the sections of the book and is not intended as a directory covering every organisation. The publications and organisations listed here will often point you to the right place. If you can't find what you're looking for locally go to one of the national carers' organisations' website or helpline. If you don't have internet access at home your local library has computers you can use and someone who can help.

www.dewis.cymru www.dewis.wales

Local Organisations

1. Your local County Council or Carers Information Service is your first ports of call for access to information and support. All produce some excellent information for carers. See below for local details.

Carmarthenshire

Carmarthenshire Carers Information Service

Email: info@carmarthenshirecarers.org.uk

www.carmarthenshirecarers.org.uk

Facebook: www.facebook.com/CarmsCarers

Twitter: www.twitter.com/CarmsCarers

Tel. 0300 0200 002

The Carers Information Service is an information, advice and support service for anyone looking after a relative, friend or neighbour. We produce and distribute information for carers and run monthly support groups. Our outreach service enables us to actively support carers to access the services and support available to help them to better manage the impact of their caring role.

Carmarthenshire County Council

www.carmarthenshire.gov.uk

Carmarthenshire Young Carers Service
youngcarersservice@carmarthenshire.gov.uk
Tel: 01554742630

Social Care Contact Centre '**Careline Plus**' – For information, advice and help from Social Care

Tel: 01267 224466 or contact them via the online referral form

The Social Care pages of Carmarthenshire County Council contain information that may be relevant to carers. For further information, visit

www.carmarthenshire.gov.uk/english/socialcare/pages/socialcarehealth.aspx

Delta Wellbeing is the way to request information, advice and help from social services:

Tel: 0300 333 2222

Ceredigion

Ceredigion County Council

www.ceredigion.gov.uk/carers

Porth Gofal is the way to request information, advice and help from Social Services. Call Porth Gofal on **Tel. 01545 574000**

The '**Carers Pack**', gives practical information about local services and, carers assessment and your rights and other helpful information, it can be obtained from Porth Gofal

On the website the following documents are available to download:

'A Carers Guide to Planning for Emergencies'

'Assessments, A Guide to getting an assessment in Wales from April 2016

'Registration of Carers with their GP Practice'

Alternatively copies are available from Porth Gofal

The Carers Magazine is a newsletter for carers in Ceredigion which is produced three times a year, is free and can be posted or emailed to you.

Pembrokeshire

Pembrokeshire Carers Information and Support Services (PCISS)

01437 611002

Email pciss@hafal.org

www.hafal.org/crossroads

Carers are invited to register with PCISS to benefit from any or all of the following:

- **Carers' Information Pack**
- **Carers' Gazette**
- **Carers' Emergency Back-up Scheme**
- **Carers' Recognition Card**
- **Carers' Outreach Support**
- **Carers' Drop-in Centre**
- **Carers' Events**

Face-to-face, telephone, on-line support.
One-to-one or in a group setting.

2. Carmarthenshire Young Carers and Hidden Harm Service offers focused one-to-one and group support to young people whose welfare is affected by their caring role or parental substance misuse.

Tel: 01554 775232

The Children & Young Adult Carers Information Service in Carmarthenshire provide practical and emotional support from a dedicated keyworker including; care planning, 1:1

support, activities, trips, youth clubs and workshops aimed at confidence building, reducing stress and building skills around resilience, healthy relationships, education and employment.

Tel: 0300 0200 002.

Ceredigion 'Young Carers (ages 8 to 18) and Young Adult Carers (ages 18 – 25) Services at Action for Children provides support advice and 'time out' for Young Carers and Young Adult Carers to enjoy social activities and to chance to meet other young carers. **Tel 01437 761330**

Pembrokeshire Young Carers Project at Action for Children provides support and 'time out' for young carers to enjoy social activities and to meet other young carers.

Tel: 01437 761330

'**Pembrokeshire Sibling Group**' provides support and activities for siblings of disabled young people

Tel: 01437 764770 or email:

pembrokeshiresiblinggroup@hotmail.co.uk

3. Carmarthenshire's Family Information Service

www.fis.carmarthenshire.gov.uk

Tel: 01267 246555

Ceredigion Children and Young People's Information Service

The Ceredigion Family Information Service (FIS) is a free, impartial service providing high quality information to children, young people, parents, Carers, grandparents and professionals throughout the county of Ceredigion.

<http://fis.ceredigion.gov.uk> Tel. 01545 574187

4. Exercise Referral Scheme - Your GP can refer you to this structured exercise scheme operated through the leisure centres if you suffer anxiety, depression or some physical health problems.

**[www.iawn.wales.nhs.uk/
national-exercise-referral-scheme](http://www.iawn.wales.nhs.uk/national-exercise-referral-scheme)**

In Carmarthenshire it is known as the ‘**Vitality Scheme**’. More information can be found on the Actif Sir Gâr website at **www.actifsirgar.co.uk** Tel: **01269 590266**

In Ceredigion it is ‘Exercise Referral Scheme’. More information from ‘**Ceredigion Actif**’ at **www.ceredigionactif.org.uk/gp** **Paul.jones@ceredigion.gov.uk** or **(01970) 633610**

In Pembrokeshire more information about the ‘**Exercise Referral Scheme**’ is on the Leisure page at **www.pembrokeshire.gov.uk**.
Tel: 01437 764551

5. **Hywel Dda University Health Board** provides healthcare services via hospitals and in the community in Ceredigion including GPs and dentists

www.hywelddahb.wales.nhs.uk
Tel. 01437 771220

6. ‘**Looking After Me**’ course available through the Education Patient Programme run by Hywel Dda University Health Board **www.eppwales.org**

Tel. 01554 779507
Email: eppcymru.hyweldda@wales.nhs.uk

7. IAWN - Hywel Dda

This website has been developed to provide information on the local primary mental health support service (LPMHSS) in Carmarthenshire, Ceredigion and Pembrokeshire. It aims to provide easily accessible online resources and information on mental health issues to enable people to self-help and know where to access further support should they need it.

www.iawn.wales.nhs.uk

Information, Awareness & Mental Wellbeing self help resources. There are teams based in primary care which provides help for people experiencing emotional distress. The service operates out of every GP practice and an initial assessment will help you decide on the best way forward. Referral is through your GP.

The Primary Care Mental Health Team also offers stress control courses which you can sign up to. Stress Control is a group class run by the new Local Primary Mental Health Support Service, established in line with the Mental Health Measure (Wales). The courses are delivered in various community locations across the county. For more information **www.iawn.wales.nhs.uk/home**

8. Book Prescription Wales – GPs and other health professionals can write a ‘prescription’ for a recommended self-help book which you exchange at any library. Subjects covered include anxiety, depression, bereavement, worrying...More information on **www.iawn.wales.nhs.uk/book-prescription-wales**

9. The **'Investors in Carers'** award scheme for GP practices. You can register yourself as a Carer with your GP surgery and ask for a referral for further help and support. All surgeries will have a Carers Registration/Referral form to be able to do this, or you can download the form from www.hywelldahb.wales.nhs.uk/carers

10. Each county has an organisation that provides services and support for older people and their families. They offer information and advice and produce a leaflet **'Advice for Carers: a practical guide'**.

Carmarthenshire: Age Cymru Sir Gâr
www.ageuk.org.uk/cymru/sirgar
Tel: 01554 784080

Ceredigion: Age Cymru Ceredigion
www.ageuk.org.uk/cymru/ceredigion
Tel. 01970 615151 (North) and
01239 615777 (South)

11. **Carmarthen:** Ty Cymorth Day Hospice offers free physical, emotional and spiritual support for patients with a life limiting condition and their families.
www.tycymorth.org.uk
Tel. 01267 235151

Alzheimer's Society provides face-to-face, telephone, print and on-line support & advice. Training, Carers' Groups and Music and Memories sessions Central number for English speakers: **0333 150 3456**;
Welsh Speakers can contact: **03300 947 400**.
www.alzheimers.org.uk

Pembrokeshire: Paul Sartori Foundation offers support, a sitting-in service and hospice at home care for people with a life-limiting illness www.paulsartori.org

Tel: 01437 763223

- 12. 'Carmarthenshire Carers Information Service'** offers information, advice & support for carers in Carmarthenshire.

Tel: 0300 0200 002

Gofalwyr Ceredigion Carers offers information and advice, practical and emotional support for all carers in the community.

Tel: 03330 143377

Email: Ceredigion@credu.cymru

'Pembrokeshire Carers Information and Support Service' offers information about support around the county.

01437 611002 Email pciss@hafal.org

- 13. Hafal/Crossroads** – provides short breaks to carers either in the home or a dedicated dementia day care setting

www.hafal.org/crossroads

Pembrokeshire: Tel. 01437 764639

Hafal-Crossroads, Crossroads House, 37 Merlins Hill, Haverfordwest, SA61 1PE

Tel: 01437 764639

Provision of replacement care in the home; in some areas in a group setting (respite clubs) delivered by trained Carer support workers to give unpaid Carers a break.

Hafal Pembrokeshire Seibiant Providing respite to Carers of people with Serious Mental Illness.

Hafal Pembrokeshire family support Providing information, advice and practical support to Carers, family and friends. Group meetings on Thursdays at 3:30pm at Bro Cerwyn.
07814756336

Cars 4 Carers Pembrokeshire

For a small cost, carers can travel by themselves or with the person they care for. If you are interested in finding out how this service can help you, please call the dedicated C4C mobile number: **07469 859029** and leave a message for Cathy, our journey co-ordinator.

In Pembrokeshire **RSVP** Welcome Friends helps people over 50 to get the most out of life.

Tel. 07733 265769 or **01437 769422**

email: revans@csv.org.uk

Tel. 01554 779910

MIND Pembrokeshire Carers Project

Specialist service that provides support based around people's individual needs. Practical support, telephone advice and support, support sessions and befriending service. Creative Carers workshops, Moodmaster sessions and Monthly Lunches and activities to address mental health. Contact: **Karina** on **01437 769982** or

07813797615 **karina@mindpembrokeshire**

Mind Llanelli also have a Carers group in partnership with Hafal.

In Pembrokeshire **RSVP** Welcome Friends helps people over 50 to get the most out of life. **Tel. 07733 265769** or

01437 769422 **email: revans@csv.org.uk**

Tel. 01554 779910

14. Cruse provides a telephone helpline, useful information and face to face support for people who have been bereaved
www.cruse.org.uk
Helpline 0808 808 1677
Carmarthenshire branch 01267 235130
Ceredigion branch 01239 621141
Pembrokeshire branch 01437 891006
Email: westwales@cruse.org.uk

15. **West Wales Action for Mental Health (WWAMH)** which covers the three counties has a directory of local organisations offering support to people with mental health problems **www.wwamh.org.uk**
Tel. 01267 245572
The West Wales Recovery book is also available from WWAMH.

National Organisations for Carers

16. Central Government information and advice for carers
www.direct.gov.uk/carers-allowance

17. **NHS Direct Wales** – Information on fitness, healthy eating, keeping stress levels down etc.
www.nhsdirect.wales.nhs.uk
Tel. 0845 46 47 or 111

18. Carers Wales is part of Carers UK, a policy, campaigning and information organisation **www.carerswales.org**
Tel. Advice Line on 0808 808 7777

19. Carers Trust – aims to offer information and support to all unpaid carers throughout the UK **www.carers.org**
Tel. 0300 772 9702

20. Carers UK publishes ‘Looking After Someone: A Guide to Carers Rights and Benefits’ www.carersuk.org
21. The Children’s Society’s ‘Include’ project
www.youngcarer.com
Young Carers toolkit: youngcarerstoolkit.co.uk

Other National Organisations

22. The Samaritans offers confidential, non-judgemental emotional support 24 hours a day www.samaritans.org
Tel. 116 123 or Welsh Language Line 0808 164 0123
Email: jo@samaritans.org
23. C.A.L.L. – Community Advice and Listening Line offers emotional support and information/literature on mental health and related matters to the people of Wales.
www.callhelpline.org.uk
Freephone 0800 132 737
24. Childline is a counselling service for children and young people. You can contact them about any problem, large or small www.childline.org.uk Tel. 0800 1111
25. TGP Cymru is a Children’s Rights Charity in Wales which supports and represents vulnerable children and young people through a range of projects, training and campaigning
www.tgpcymru.org.uk Tel. 029 2039 6974

26. **Wales Dementia Helpline** offers emotional support to anyone, of any age, who is caring for someone with dementia as well as other family and friends. The service also helps and supports those who have been diagnosed with dementia. **www.callhelpline.org.uk** or freephone **0808 808 2235**

27. **Alzheimer's Society** has an article on 'Dealing with Guilt' **www.alzheimers.org.uk**
Tel. 0800 222 1122

28. Relate offers advice and relationship counselling for all relationships in difficulty
www.relate.org.uk
Tel. 0300 100 1234

29. AgeUK offers information and advice to improve later life for everyone. The 'LifeBook' is a free booklet where you write important and useful information about your life
www.ageuk.org.uk
Tel. 0845 685 1061

If you want information or support for a particular medical condition an internet search will bring up the main organisations. Their websites all have a section for carers offering more specialist advice.

Health and Wellbeing

32. **NHS Direct Wales** – for information on a wide range of health problems, healthy living advice and local services
www.nhsdirect.wales.nhs.uk
24 hour telephone advice service – **0845 46 47** or **111**
31. **Health Challenge Wales** – advice on healthy lifestyles
www.healthchallengewales.org
32. **Mental Health Foundation** – Information about mental health, looking after your own, podcasts for wellbeing and relaxation, information about mindfulness (including an online course) and resources to help you sleep better
www.mentalhealth.org.uk or **bighealth.com**
33. **‘Living Life to the Full’** is a free on-line course that teaches you ways to develop life skills to tackle low mood, stress and distress **www.lltff.com**
34. Young Minds is a charity that helps to improve the mental health of young people **www.youngminds.org.uk**
35. **NHS Direct** has information on all aspects of healthy eating
www.nhsdirect.wales.nhs.uk

- 36. Food and Mood** – information about how to improve your mental wellbeing through changes to diet and eating habits
www.mind.org.uk/information-support/tips-for-everyday-living/food-and-mood
Dan 24/7 is a free bilingual helpline for anyone wanting information or help relating to drugs or alcohol.
www.can247.org.uk
Tel. 0808 808 2234
- 37. Stop Smoking Wales** – confidential free support to stop smoking
www.helpmequit.wales
Tel. 0808 252 8307
- 38. Counselling Registers** – The British Association for Counselling and Psychotherapy and the UK Council for Psychotherapy hold details of registered counsellors and psychotherapists
www.bacp.co.uk
Tel. 01455 883300
www.psychotherapy.org.uk
Tel. 020 7014 9955
Carmarthenshire Counselling Service
Tel: 01554 772385
carmarthenshirecounselling@yahoo.co.uk
- 39. Complementary Therapies** – To find a practitioner consult the national register of the therapy you are interested in.
- 40. OpenLearn** from the Open University offers over 600 free online courses from introductory to postgraduate level
www.open.ac.uk
Contacts for Practical and Financial Support
www.psychotherapy.org.uk
Tel. 020 7014 9955

41. **Complementary Therapies** – To find a practitioner consult the national register of the therapy you are interested in.
42. **Department for Work and Pensions** – provides financial support for people claiming disability benefits and their carers: www.gov.uk
Carers Allowance Unit 0800 731 0297
Carers Allowance Digital Allowance:
www.gov.uk/apply-carers-allowance
Job Centre Plus – offers work-focused support for carers
0845 604 3719
43. **Citizen’s Advice Bureau** helps people resolve their legal, financial and other problems by providing free, independent and confidential advice
www.citizensadvice.org.uk
44. www.moneysavingexpert.com – an independent website that helps you save money.
45. **Books**
There are many books available on the subject of caring as well as condition specific books, website etc. We do not want to recommend or suggest any however if you look online or visit your local library I am sure this would help.
The Library Service in each county has an on-line catalogue
www.carmarthenshire.gov.uk
www.ceredigion.gov.uk
www.pembrokeshire.gov.uk
Ceredigion Carers Booklist and the Pembrokeshire Carers Booklist is a resource which suggests books for Carers to read. Copies are available from the Ceredigion or Pembrokeshire Library Service or on the website
www.ceredigion.gov.uk/carers.

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Mind Your Heart



An edition for the three counties was published in 2012 under the Hywel Dda Region Carers Measure Information and Consultation Strategy 2012. This fourth edition is an update published as a partnership between:



Cyngor Sir
CEREDIGION
County Council



Notes