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# A positive guide to life after your dementia diagnosis



Changing  
perceptions  
of dementia

*effro*

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## About us

Effro is a project from the mental health and social change charity Platform. We aim to change perceptions surrounding dementia-related conditions, and fight against the outdated systems that can prevent people with dementia from achieving their full potential in life.

It's our belief that people living with dementia should have the opportunity to live life on their own terms. Rather than only taking a medicalised approach, our vision is for a world where individuals living with dementia are listened to and supported to lead purposeful, enjoyable lives based around their interests and ambitions.

**This booklet aims to provide useful tips and friendly advice for people living with dementia.**

**It includes guidance on where to find information and support, ideas for practical things you can do to plan for the future and lots of positive ways to continue leading a healthy, happy life.**

**Whatever your situation, we hope the following pages provide some help and optimism for the future.**

# How are you?

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**Pause for a moment.  
Consider this question seriously.**

## **How are you feeling?**

Receiving a dementia diagnosis is an undeniably life-altering moment. Whatever you're feeling, it's OK to let it out. It's OK to not be OK. Most of all, it's OK to ask for help when you need it.

A life with dementia is still a life, and the experiences you've lived up to this point will always be part of you, no matter what the future holds.

# Life following a dementia diagnosis



There's no right or wrong way to feel when you've been diagnosed with dementia. You're likely to experience a wide range of emotions: shock, fear, denial, anger, guilt, sadness, perhaps even relief that there's a logical explanation for what you've been experiencing.

Whatever your reaction, **you are not alone.** More than 50 million people around the world live with dementia. While it may not be easy to come to terms with your diagnosis, dementia doesn't mean the end of a happy, fulfilling life.

There's no rush to process what you're feeling. Take as much time as you need. When you're ready, there are a number of things you can do to learn more and plan ahead.

## Who to talk to

Talking to family and friends can be a great source of comfort and reassurance following a dementia diagnosis. If you need someone else to talk to, GPs and dementia professionals are there to help – they may talk through your concerns with you or refer you to another specialist.

There are also charities that provide a free listening service for anyone affected by dementia. You can find the contact details for some of these organisations on the back page of this booklet.

## Practical considerations

Planning for the future can be tricky, but it's important to think ahead and communicate your most important wishes as soon as possible.



### Some of the things you might like to consider include:

- > Telling friends and family about your diagnosis
- > Putting your financial affairs in order to minimise future stress or confusion
- > Considering whether you will need help in your home, or adaptations to make your home safer
- > Making a list of local support services
- > Claiming any benefits you may be entitled to
- > If you drive, informing the DVLA and your car insurance company (you may not need to give up driving right away, but might need to attend an assessment)
- > If you work, informing your employer (they may be able to make adjustments so that you can continue working)
- > Making a will
- > Appointing someone to make decisions and manage your affairs if you begin to find things difficult

### Where to find information

For some good places to find information online, check out the back page of this booklet. We also have an excellent website packed with information and videos. Find us at [effro.org](http://effro.org).

Your local library may be able to recommend some books that provide useful and practical information about dementia. If you have a specific question about your condition, you could also ask your GP or occupational therapist.

# Planning ahead

While everyone's situation is different, taking some practical measures to ensure that your needs are met and your wishes are respected can be an empowering first step to life with dementia. Here are some practical ideas to help you plan for the future.



## Create a wishlist

What are the things you've always wanted to do, but somehow never got around to? These are the things that will bring you lasting joy and satisfaction in life, and you deserve to experience them. From revisiting a favourite holiday destination to booking a fancy afternoon tea with your nearest and dearest, make a list of your dreams and ambitions. Then make plans to experience them as soon as possible.

## Identify joyful activities

Along with happy memories of past events, the hobbies and passions that continue to bring us fulfilment are an essential component of a happy life. Take some time to identify what these activities are for you, and make sure the people around you know about them. Maybe you're at your happiest immersed in nature, or feel most alive when you're listening to your favourite records. Perhaps there's an old hobby you'd love to revisit, or an artistic talent you long to explore. Whatever sparks joy in your heart, put plans in place to ensure that you continue to experience it.

## Construct a memory box

We've all got fond memories that we enjoy revisiting from time to time. We may also have physical reminders that trigger the happy feelings we associate with those memories. Photos from special days, tickets from thrilling sports matches and concerts, certificates of proud achievements, sentimental objects that take us back to our childhood – these magical items exist to rekindle the joy we originally felt. Start collecting and storing these objects in your own personal memory box; a collection of precious items that will provide feelings of warmth, comfort and nostalgia whenever you need them.

## Share your wishes

As dementia progresses, other people may assist you in providing the things you need and want on a day to day basis. The way you like your tea or coffee prepared, your preferred style of clothing, a TV programme you watch every day (or one you'd prefer to switch off) – these small decisions and habits enable you to maintain your sense of belonging and identity. It's important to communicate these wishes as soon as possible. No matter how big or small, asking people to respect your personal preferences will allow you to continue living comfortably without regret.

## Consider your culture

Your cultural background, heritage, race, language and religion are all important aspects of your personality. Take some time to consider how these things affect your day to day life, and talk about them with those you trust. Try to make sure the people closest to you understand your language, values and beliefs, and ask them to make sure that these aspects of your identity continue to be respected.

For more information and resources on different cultures in Wales, visit [diversewales.org.uk](http://diversewales.org.uk)

## Set healthcare reminders

Taking care of your physical health is particularly important following a dementia diagnosis. Setting some simple reminders can be helpful to make sure all your basic healthcare needs are taken care of. Scheduling regular dental appointments, eye tests, hearing tests and mobility check-ups will help to reduce the chance of health-related problems arising, such as tooth pain affecting eating or walking difficulties making it tricky to exercise.

## Develop healthy habits

Eating a balanced diet. Drinking lots of water. Exercising daily. Getting enough sleep. Avoiding alcohol, drugs and smoking. These deceptively simple tips for a healthy lifestyle can make a huge difference to your wellbeing with dementia. You don't have to make radical changes to introduce these positive habits – start by aiming for a piece of fruit each morning, a glass of water with every meal or a daily walk around the block. As these habits become part of your regular routine, they may become easier to remember and follow.

## Simple changes at home

The way your home is arranged can make a big difference to your quality of life with dementia. Start with some simple changes, like installing a big whiteboard where you and others can write down important reminders and essential everyday information. Labelling commonly used amenities and objects around your home (such as hot and cold taps or the contents of cupboards) can help to make life easier. It's also a good idea to get someone to regularly check your smoke alarms and gas detectors to keep your home as safe as possible.



# A life well lived



**Expressing yourself creatively. Engaging your body in physical activity. Enjoying quality time with friends and family. Embracing the wonders of nature.**

These are the everyday things that bring joy to life, and you can continue to experience them all while living with dementia.

Along with your day to day activities, a range of approaches and therapies have been shown to improve the lives of people who live with dementia.

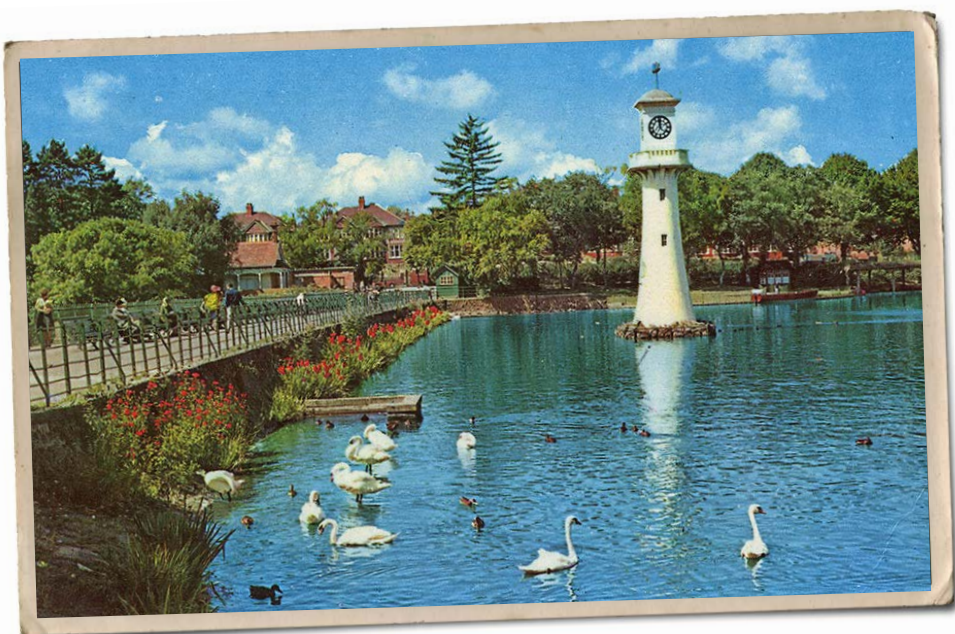
These include reminiscence therapy (using the senses to recall previous events and experiences) and cognitive stimulation therapies (structured activities that help people living with dementia to improve their memory and thinking skills).

The following pages outline a variety of therapies, activities and ideas that you can use to continue living your best life, no matter what the future holds.



## Reminiscence therapy

### Using joys from the past to inspire present-day happiness



Reminiscence therapy is one of the most effective therapies for people living with dementia. The premise is simple: by sharing memories and stories of the past, you're reminded of the happy times you've lived through and feel comforted by the joy of remembering.

Since it's more common for dementia to affect our short term memories, reminiscence therapy can help you to feel empowered and confident that you're still able to recall things that happened a long time ago.

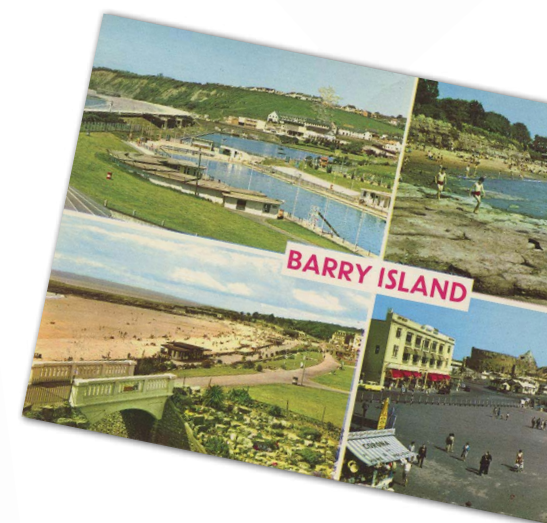
The experience can be made even more powerful by using the senses – introducing elements of sight, sound, scent, taste and touch to transport you back to an experience that may have happened many years ago.

If you're struggling to come up with a memory that brings you happiness, using objects from the past can sometimes help. For example, if you don't remember much about a holiday you once enjoyed, observing a photograph might prompt your mind into recalling the emotions you felt.

### Try it yourself

Try to think of a time in your life when you felt at your happiest. It could be a holiday, a celebration, a visit to a special place or something completely personal to you.

- > What were you doing, who were you with, and where did you experience the event?
- > What sights, sounds, scents, tastes and textures do you remember from that special time?
- > Do you have any photographs or souvenirs that might help you to recall even more about the event?



**Strolling the shoreline with the sun on your skin and sand between your toes, inhaling salty air between sweet sips of lemonade, serenaded by squawking seagulls and nostalgic fairground sounds.**



**How might you experience some of the same feelings by using your senses? For example, you could:**

- > Look at a photograph of a special place you've visited
- > Listen to a song that reminds you of a happy time
- > Smell some flowers, herbs or spices that trigger a memory
- > Eat some flavourful food that you associate with a memorable life event
- > Feel the fabric of some clothes you wore on a special day
- > Visit places that are meaningful to you

### **Not Forgotten**

To see the positive power of reminiscence therapy, take a look at Not Forgotten, an exhibition of memories and stories shared by people living with dementia in Cardiff. Films that were produced as part of Not Forgotten can be viewed on our website: visit [effro.org](http://effro.org) to watch them.

## Cognitive stimulation therapy

### Stimulating activity sessions that engage your memory and thinking skills



Keeping our minds active and engaged is important for our mental wellbeing – this is the main principle behind cognitive stimulation therapy. Often abbreviated to CST, it's a complex-sounding name for a set of fun and sociable activity sessions, designed to stimulate your mind as an effective therapy for the symptoms of dementia.

As well as helping your thinking and memory skills, attending CST sessions is a great way to make friends and stay sociable in your community.

They provide a relaxed environment where you can be yourself, express your views and talk to others while working through a range of fun, structured activities.

#### **The kinds of activities you might enjoy at a CST session include:**

- > Discussing recent news stories as a group
- > Listening to music or singing
- > Playing word games and quizzes
- > Taking part in creative activities like painting and modelling
- > Baking tasty treats like cookies and cakes



#### **Find out more**

There are opportunities to attend CST sessions in a variety of places around Wales. To find out about any groups running in your local area, ask your GP or occupational therapist for details, or contact one of the organisations on the back page of this booklet.

## Maintaining independence

### Continue living life on your own terms

There's a common misconception that people living with dementia need support in every aspect of their lives.

How much assistance you may need can change over time. Some tasks may require a little more, some a little less, but keeping as independent as possible is a great achievement.

There are a wide range of everyday activities that you may still be able to handle yourself while living with dementia. Here are a few examples.

#### Paying in shops

Taking care of your own money and paying for items in shops, cafés or restaurants is an empowering way to maintain your independence with dementia. Don't worry if it takes you a little longer to find the right change, or if you need to ask a few questions before you make a purchase. Most shop workers will be happy to assist you when you're buying the things you need.

If you don't feel confident using cards or carrying money, try having a small pouch that you keep a set amount in, or use a pre-paid card.



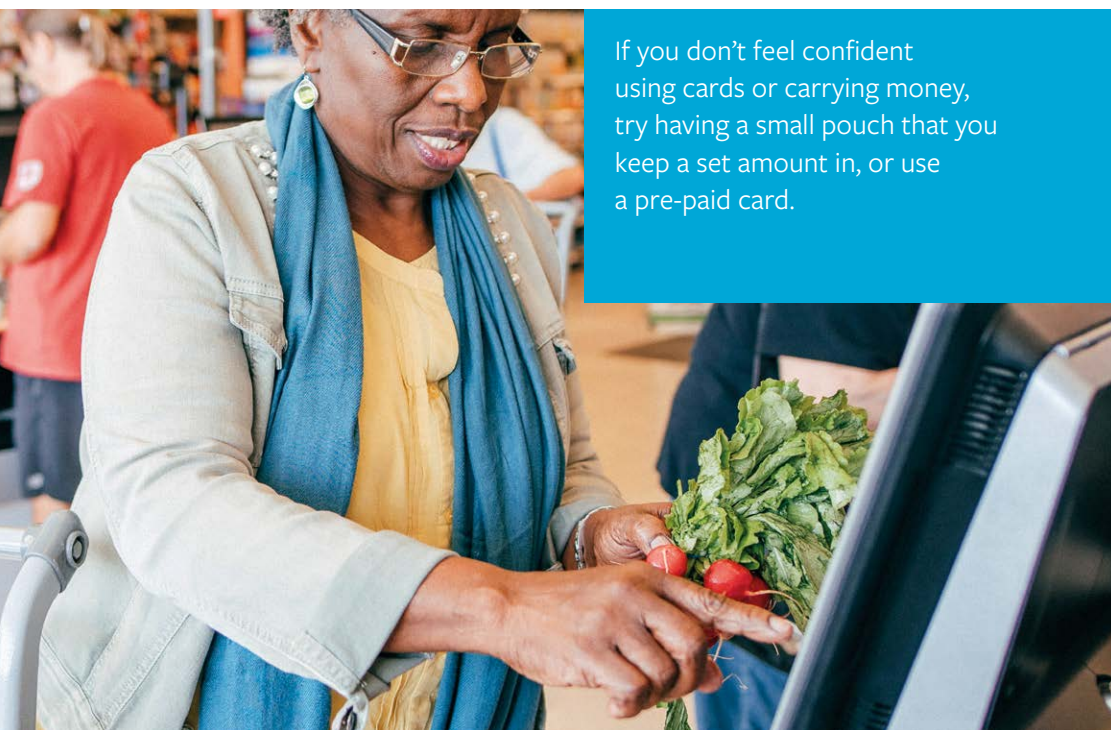
#### Travelling on public transport

Being able to take a bus or train to visit local places and see friends or family is something that's perfectly possible while living with dementia. Depending on the type of dementia you've been diagnosed with and your current experiences of it, you may prefer to travel alongside a friend or family member. Regardless of whether you're travelling alone or with someone else, getting out and seeing the world is an everyday pleasure that you shouldn't deny yourself.



#### Preparing food

Whether it's a simple snack or a hearty meal, the food we eat on a day to day basis can have a big impact on our quality of life. Equipping yourself with a go-to list of tasty recipes that you know how to prepare yourself is a great way to take control of your diet and maintain a sense of independence. Aim for a healthy, balanced range of food that's easy to prepare and will keep you feeling good about yourself.



## Remaining active

### Exercise your body to feel mentally and physically well



The benefits of physical exercise cannot be overstated, especially following a dementia diagnosis.

No matter your age or ability, staying active is important for both mental and physical health, releasing chemicals in your brain that promote positive thinking while keeping your muscles and joints strong.

You don't need to run marathons or climb mountains to stay fit. There are lots of simple things that you can do to keep yourself active, from gentle walks to invigorating sports.

**Physical activity is shown to increase brain activity, allowing for better focus and faster information processing.**

#### Activities at home

Some exercises can even be enjoyed from the comfort of your home – visit [elderfit.co.uk](http://elderfit.co.uk) for activity ideas and video workouts.

## Join a walking group

Walking as part of an organised group is a brilliant way to keep both your body and social life active. Making friends while getting out in the fresh air and seeing new places are all great ways to maintain a healthy and balanced lifestyle. And you don't need to be a power walking athlete to take part – many groups exist for those who prefer a more gentle pace, with lots of rest stops along the way.



## Play some sports

If you love sport, there's no better way to get active than to join a local club. Team games like football, hockey and basketball are great for mixing exercise with social activity. Table tennis and badminton are brilliant all-weather sports that can improve your hand-eye coordination. If you're feeling adventurous, you might even try rock climbing – activity centres often hold introductory sessions where you can be shown the ropes in a fun and supportive environment.

## Swim, cycle or run

The classic triathlon of swimming, cycling and running provides a great full body workout, but you don't need to do all three to feel the benefit. These activities are easy to get involved with – many villages and towns have a local swimming pool, and you can cycle or run almost anywhere. Of course, pool and road safety are important, so if you don't feel confident exercising alone, you can always bring along a friend or family member to be your workout buddy.



## Getting creative

Express your creativity through a range of artistic hobbies



The right side of your brain is often thought of as the creative side, where clever ideas are formed and problems are solved.

What many people don't realise is that the right side of the brain is also responsible for your memory and attention. Taking part in a creative hobby can therefore be a great way to keep this side of your brain active and healthy.

There are all kinds of ways to get creative. Perhaps you've already got a hobby you'd like to take further, or you're a creative newbie keen to try out some new things. Wherever you're at in your creative journey, the most important thing is to enjoy yourself. Here are some ideas to get you started.



## Craft your own masterpiece



Painting, drawing, sculpting, modelling, sewing, knitting... there's no end to the number of fun and hands-on crafts you can take part in these days. You don't need an artist's studio to get started either – materials can be bought cheaply, or you could attend a group where everything you need is readily available. It doesn't even matter if you're not very good – the fun of making something with your own two hands is a reward in itself.

## Learn photography

There's never been a better or easier time to take up photography as a hobby. Most modern mobile phones double as cameras, so you don't need to buy any expensive kit to start snapping. Simply head to a local place with lots of interesting things to look at and take some photographs of the stuff you see. Sharing the pictures you've taken with friends and family can be a fun way to get others involved.



## Make some music



Music is a universal language. No matter where you're from or what you've experienced in life, the melodies and rhythms in songs have the potential to make us feel all sorts of emotions. Playing music on an instrument can be an empowering way to express what you're feeling, and can even act as a form of therapy. If you don't fancy learning an instrument, you could always try singing – there are choirs for people of all abilities, and there's something wonderful about belting out your favourite songs with a group of friends.

Visit  
[forgetmenotchorus.com](http://forgetmenotchorus.com)

## Experiencing nature

### Surround yourself with plants and wildlife to boost your wellbeing

Nature exists within all of us. We're literally part of the natural world, so it makes sense that we feel at home when immersed in wild landscapes, populated with lush greenery and scurrying, fluttering animals.

Spending time outdoors connecting with nature is proven to be a positive influence on our mental health. For those living with dementia, nature takes on an even greater role – it's a reminder that living in the present moment is a wonderful thing, no matter what we've experienced in our past or what the future may bring.

Since nature is everywhere, you don't need to go far to find it. You can connect with nature in a local park, a nearby woodland or your own back garden. Wherever you experience it, the natural world will always provide something special for you to enjoy.



### Get green fingers

Nothing connects you with the natural world quite like growing your own plants. Sowing seeds and watching them spring to life with green shoots and vibrant blooms never gets old. Why not begin with these easy garden growers?

**Poppies**  
**Daffodils**  
**Sunflowers**  
**Lavender**  
**Rosemary**  
**Mint**  
**Holly**  
**Acorn**

**Magpie**  
**Blue tit**  
**Robin**  
**Ladybird**  
**Butterfly**  
**Squirrel**  
**Sparrow**  
**Bee**  
**Duck**  
**Swan**

### Spot some wildlife

We share our environment with all kinds of interesting animals. Spotting and identifying the wildlife in your area can be an absorbing and life-affirming activity. To kickstart this new hobby, try identifying these common creatures in your local park or green space.



## Embracing technology

### Use everyday gadgets to connect with the things you love

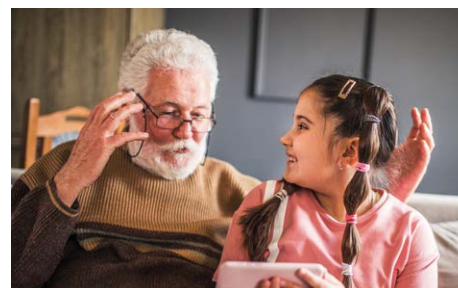


Smartphones have revolutionised the way many of us connect with the world. Photographs, videos, music, stories and conversations are all available on an object that fits neatly into your pocket.

Thanks to these handy devices, it's never been easier to connect with things we care about. If you're living with dementia, a smartphone or other internet-enabled device can give you access to your hobbies and interests, providing you with images and sounds that relate to your passions.

What's more, smartphones and similar gadgets are excellent tools for reminiscence. You can use your device to revisit happy moments of the past – photographs of loved ones and favourite places, videos of memorable events and the sounds you associate with fond memories (gentle ocean waves or a chorus of birdsong, for example).

You can find musical resources, and information on other activities, at [effro.org/online-programme](http://effro.org/online-programme)



## Connect with your memories

Various smartphone apps exist that can be used to revisit and enjoy happy memories. For example, the NHS-approved My House of Memories app has been designed specifically for people living with dementia: it allows you to browse through a selection of objects from the past, complete with sound effects and videos that bring each item to life. You can download the app for free on most smartphones from the App Store or Google Play.



## Experience life from afar

One of the best things about modern technology is that it allows us to experience things remotely, even if we're miles away. For example, if you're interested in wildlife, many zoos offer online webcam experiences that allow you to watch real-time footage of amazing animals, from pandas and polar bears to giraffes and elephants. You could also become a virtual tourist by viewing live streams of faraway places, or by using tools like Google Street view to remember old favourites.





## Staying social

### Maintain an active social life to enjoy friendship and avoid isolation

One of the most common fears following a dementia diagnosis is that of becoming socially isolated. We humans are sociable animals, and many of us need to be around other people to feel at our best. It's therefore important to avoid losing touch with those closest to you, and to continue connecting with members of your community.

There are a variety of ways to do this. If you have family or friends nearby, expressing your desire to see them regularly and scheduling

frequent visits will ensure that you always have a social call to look forward to. Attending local groups or joining a club is another way to stay socially active – combining a hobby with the chance to meet people could lead to new friendships flourishing.

If you're suffering with loneliness, there are charities and support groups that can help; we've included the contact details for some of them on the back page of this booklet.

## Form new friendships

From sports to arts and crafts, we've already covered lots of things you might choose to enjoy in your free time. These activities become even more fun when you combine them with a social event – joining a local club, group or class themed around something you're interested in is a brilliant way to meet people and make friends. Many organisations cater for people living with dementia, so you needn't feel isolated or alone.



## Keep in touch with loved ones

Making time to see family and friends becomes even more important when you're living with dementia. People have busy lives, but there aren't many things more valuable than spending a few hours with those we love. You can plan for regular visits by working with your friends and family to find a weekly or bi-weekly slot when you're both available. This helps to avoid people becoming double-booked or struggling to find a time that works. Once you've decided on a regular schedule, seeing your loved ones simply becomes part of your regular routine.



# Positive times ahead



We hope the information in this booklet has helped to provide some reassurance and positivity following your dementia diagnosis.

Living with dementia comes with a variety of challenges, but with the right support and an optimistic outlook, you can continue to lead a happy and fulfilling life.

You're not alone on this journey. Many organisations and resources are available to provide support during difficult times. We've included the contact details for some of them on the final page of this book.

You can also visit our website at [effro.org](http://effro.org) for more information, videos, activities and to get in touch with our team.

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## Key facts about dementia

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**Dementia isn't a single condition: it describes a number of conditions that affect the brain.**

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**There are over 200 recognised conditions and causes that fall under the category of dementia.**

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**The most common types of dementia include Alzheimer's disease, vascular dementia, frontotemporal dementia and dementia with Lewy bodies (DLB).**

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**More than 50 million people around the world live with dementia. This number is expected to triple by the year 2050.**

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**Some of the most common symptoms of dementia include memory problems, struggling to process information, communication difficulties and changes in mood or personality.**

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**Dementia isn't only diagnosed in older people – early onset dementia can affect individuals before the age of 65.**

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**People diagnosed with dementia can continue to lead happy and fulfilling lives. Staying mentally, physically and socially active while regularly taking part in hobbies and activities can help to slow the progression of dementia.**

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**A new case of dementia is diagnosed approximately every three seconds.**

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**It's possible to have more than one type of dementia.**

## If you need to speak to someone today

### **The Silver Line**

Free confidential helpline providing information, friendship and advice to older people, open 24 hours a day, every day of the year.

Phone: **0800 470 8090**

Website: [www.thesilverline.org.uk](http://www.thesilverline.org.uk)

### **Samaritans listening service**

A safe place for you to talk any time you like about whatever's getting to you.

Phone: **116 123**

Website: [www.samaritans.org/wales/how-we-can-help/contact-samaritan-talk-us-phone](http://www.samaritans.org/wales/how-we-can-help/contact-samaritan-talk-us-phone)

## Support in a crisis

### **CAVAMH community mental health teams for older people**

First-line assessment, follow-up treatment and care for patients in the community with dementia, and elderly people with other mental health problems in Cardiff and the Vale of Glamorgan.

Phone: **02920 222 000**

Website: [www.cavamh.org.uk/directories/mental-health-directory/mental-health-services-for-older-people](http://www.cavamh.org.uk/directories/mental-health-directory/mental-health-services-for-older-people)

### **Cwm Taf Morgannwg community mental health teams**

A range of primary, community and inpatient services for adults across the localities of Rhondda Cynon Taf, Ely and Merthyr Tydfil.

Phone: **01443 443 712**

Website: [www.cwmtafmorgannwg.wales/services/mental-health/](http://www.cwmtafmorgannwg.wales/services/mental-health/)

## Further support

### **Admiral Nurse dementia helpline**

Anyone with a question or concern about dementia can call the Admiral Nurse dementia helpline for free.

Phone: **0800 888 6678**

Website: [www.dementiauk.org/get-support/dementia-helpline-alzheimers-helpline](http://www.dementiauk.org/get-support/dementia-helpline-alzheimers-helpline)

### **Dementia Connect support line**

Personalised information, support and advice provided by Alzheimer's Society.

Phone: **0333 150 3456**

Website: [www.alzheimers.org.uk/dementia-connect-support-line](http://www.alzheimers.org.uk/dementia-connect-support-line)

### **Dewis Cymru**

An online directory of wellbeing support and advice services for people living in Wales.

Website: [www.dewis.wales](http://www.dewis.wales)

## Contact us

A friendly face. A reassuring voice.  
An attentive ear. Our team understands life with dementia – no matter what you need, we'll be there for you.

0300 303 5918

[effro@plattform.org](mailto:effro@plattform.org)

[effro.org](http://effro.org)



Ariennir gan  
**Lywodraeth Cymru**  
Funded by  
**Welsh Government**

**Effro is a project from the mental health and social change charity Platform.**

Having connections, aspirations and a sense of purpose is essential to wellbeing. Our projects at Platform work with people to achieve this, and provide support networks wherever needed.

Effro plays an important role in Platform's aims by supporting people living with dementia, working with each individual to help find ways they can lead a life centred around their interests and ambitions.