



The Memory Guide

What to do following a diagnosis of Dementia?

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Living Well with Dementia Service

c/o Memory Technology Library,

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Clonmel, Co Tipperary

Published 2019

About The Living Well With Dementia Service

Living Well with Dementia in South Tipperary, based on the Grounds of South Tipperary General Hospital, Clonmel is a support service for people with dementia and their families. It is funded by the HSE and administered by Family Carers Ireland. In 2018 additional funding was received from the National Dementia Office to develop and deliver post diagnostic supports including a memory rehabilitation programme and psychoeducation programme.

Services available include:

- Access to Dementia Nurse Specialist for advice, information & signposting services
- Memory Technology Library & Occupational Therapist consultation
- Dementia Support Worker Service
- Training & Education (healthcare professionals, formal and informal carers)
- Six week memory rehabilitation programme for people recently diagnosed with mild dementia
- Five week psychoeducation programme for people with mild/moderate dementia

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Foreword

Going to the doctor and getting a medical diagnosis of any kind can be very daunting and upsetting. When it comes to dementia some people experience shock while others may experience an initial sense of relief at finally being able to put a name to their symptoms. Whatever the immediate response usually people will experience a range of different emotions over time.

In the past people may not have been told they had dementia because we didn't understand it as much as we do now. But we know now that there are medications and other interventions that can help manage and lessen the symptoms. That's why getting a diagnosis and being able to talk about it is a good thing. A diagnosis also benefits the wider family and enables them to understand what is happening and how they can help.

This handbook is a practical guide that aims to help you understand your diagnosis and provide you with practical information that can help you manage symptoms and live well.

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SECTION 1

**Understanding
how your
memory works**

How Memory Works

Memory is very complex. It is made up of a group of systems that each plays a different role in creating, storing, and recalling your memories. We use different types of memory when we do different things.

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Knowing a little about how memory works helps us to understand dementia better and recognise how using strategies and routines can help us to better manage some of the symptoms.

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Types of Memory

1. **Working Memory** often referred to as short term memory allows us to store small amounts of information for short periods (2-18 seconds). It's for remembering things in the present moment. Items can be kept in working/short term memory long enough to use them by repeating them verbally, a process known as rehearsal. For example, remembering a phone number in order to make a phone call.

If you have problems with your working/short term memory you may have difficulty following instructions, take longer to figure something out, for example adding up numbers or difficulty remembering items from your shopping list.

2. **Long Term Memory** has more capacity to hold information. It is divided into different categories. It is needed to:

- I. recall past events (recent or distant), such as personal experiences, emotions and feelings.
- II. remember the meanings of words or facts.
- III. remember an appointment, date or event that is due to happen in the future.
- IV. complete activities we learned and can do automatically, without having to think. For example, tying your shoelaces, riding a bike.

If you are having problems with your long term memory, depending on which category of long term memory is affected you may have difficulty recalling recent events such as a function you attended a few days ago; remembering events in the past; finding the right words when talking to somebody; remembering what you had planned to do or remembering how to complete certain tasks.

How do we create memories?

The first step in creating a memory begins with perception. You get a piece of information that is **received** through your senses which include sight, smell, taste, touch and hearing. Consider, for example the memory of meeting somebody close to you for the first time. When you met that person you may have noted the colour of their hair or eyes, the sound of their laugh, the scent of their perfume or the touch of their hand. Each of these sensations travel to different parts of your brain which converts this information into a form that can be stored. It is first held in your short term memory. This process is called **encoding**.

To first encode a memory you must be paying attention. Since you cannot pay attention to everything all of the time, much of what you encounter every day is simply filtered and only a few messages retained. Attention

allows you to “tune out” information that is not relevant at that moment and instead focus your energy on the information that’s important. This information is gradually transferred to your long term memory. The more the information is repeated or used, the more likely it is to eventually end up in long-term memory, or to be **stored**.

When you want to remember something, you must **retrieve** the information stored in your long term memory.

Memory problems can be caused by something going wrong at any of the stages described above. Also, because our senses are such an important part of memory, problems in any of these areas for example, sight or hearing can make your memory symptoms worse. It is important that you get your sight checked regularly and arrange a hearing test if needed.

There are several reasons why somebody might experience memory loss. This handbook looks at dementia. Receiving a diagnosis of dementia can be frightening, but it just means you’ll need to take action to adjust to a new normal.

Taking these five critical steps will help you manage your diagnosis:

1. **ACKNOWLEDGE** your feelings and take care of your emotional needs.
Read **Section 2**
2. **LEARN** about dementia. Read **Section 3**
3. **MAKE** the necessary changes that can help you stay healthy and may help slow down or lessen symptoms. Read **Section 4**
4. **LOOK** at what will make things more manageable day to day.
Read **Section 5**
5. **LOOK** at what will make things easier in the long term. Read **Section 6**

SECTION 2

Receiving a diagnosis of dementia

– Dealing with emotions

Getting a diagnosis of dementia even where you may have suspected it can come as a huge shock. It is normal to experience a wide range of different emotions. There is no 'right' or 'wrong' way as to how you should feel.

Some of the feelings you might experience include:

Disbelief/Denial: These are common reactions, but sometimes this can be a good thing. It can give you the time you need to deal with your diagnosis. It may take you a while to be able to talk to others about it or you may not wish to talk about it at all.

Sadness/Loss: You may feel that you will no longer be able to do the things you enjoy or had planned to do.

Fear: You might feel frightened for the future and how you and your family might be affected.

Anger: You may question why this has happened to you and not to somebody else and feel angry and resentful.

Isolation: You may feel that people do not understand what you are going through and you may not feel like meeting people.

Relief: You might even feel a sense of relief as you can now have a cause of the symptoms you have been experiencing.

Whether you experience some or all of these emotions, it's important to find healthy ways to deal with them. Here are some tips that can help:

1. Talking about it can help. Think about who you would feel comfortable talking to about your diagnosis (see the section below about sharing your diagnosis). Finding a support group and meeting others in a similar position can also help. **Let's Talk Tipperary Memory Support Group** for people living with early stage dementia meets every Wednesday morning in Place 4 U Cafe, Clonmel.

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Telephone:
087 0550050
for more information

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2. The **Alzheimer Society Helpline** is also available on **1800 341 341**. It is important for you to know that you are not alone.
3. Find out more about dementia, but don't allow yourself to be overwhelmed by information. A good place to start is by contacting the Living Well with Dementia Service located in the Memory Technology Library Clonmel. They can help you understand the diagnosis better and help advise you about what actions to take (these are discussed in the following sections).

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Telephone:
087 0550050
for more information

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4. The Alzheimer Society of Ireland also provides a Dementia Advisor Service. The dementia advisor for the Munster region is Amy Murphy who can be contacted at 086 7812217.
5. It is not uncommon for people to feel low when they are first diagnosed with dementia. Anxiety about the future and the effects of memory loss or other symptoms can weigh heavily upon the mind. Find ways to manage any stressful feelings. Most people feel much better after some exercise while some people find going for a massage or reflexology can relieve tension. Some others find having a chat over a cup of coffee therapeutic. Find out what works best for you to relieve negative thinking and stress.
6. If feelings of sadness and low mood persist make an appointment to see your doctor to discuss whether these feelings could be depression or anxiety. Both can be successfully treated.

Sharing your diagnosis

Sharing a diagnosis of dementia is probably easier than it was before because there is much more awareness and understanding of it now among people. That being said, there are still some people who are misinformed and their lack of knowledge about dementia can cause them to say things that can cause offence. Sometimes people just don't know what to say and might think they are making you feel better by saying "sure I have a bit of that myself" or "my memory is much worse than yours". Some may not want to accept the news at first and be in denial, while others will want to help. Expect different reactions from people. However, remember most people want to do the right thing and support you whatever way they can.

When you are ready, think about who you should tell. The people who are closest to you are usually the people to tell first. You would likely want them

to be aware of this change in your life, just as you would with any major illness. Tell the people with whom you are most comfortable. Tell the people who need to know.

1. Family and friends

Be honest about how you feel. Let them know what you need and how you want to be treated. If you need help, ask for it. If you need family members to leave you alone, to give you some space, let them know that. Speak up.

Just as you are coping with the changes brought on by dementia, your family members also have to adjust. Give them time. Encourage them to learn more about dementia.

Consider also sharing your diagnosis with your close friends. Friends need to know how you are doing. If people are keen to help, let them know that you'll call on them when you need them. Letting people help will be key to managing your condition.

2. Talking to other people with dementia

You don't have to tell everyone you meet about your diagnosis. Just mention it to those you feel most comfortable sharing it with.

However, there may be occasion when telling other people can be helpful. The following is a quote from a person recently diagnosed who was having problems using the bank:

"I found when I went to the bank I would get flustered if there was a big queue. If the bank clerk asked me too many questions my mind would go blank as I would be so anxious. One day I went to the customer services desk and explained my situation. They were so helpful. Now when I go in I can go straight to the customer services desk and the person on duty helps me with any transactions if I need help. They also helped me to arrange for all my bills to be paid by direct debit. All my bills are paid on the first week of the month which makes managing my finances so much easier. This has taken all the stress away."



SECTION 3

Understanding dementia

What is dementia?

Dementia is not a normal part of ageing. It is the name for a range of symptoms which cause damage to the brain. This damage causes a decline in cognitive abilities and can affect memory, thinking, language and cause challenges carrying out everyday tasks. Changes are usually small to start with and progress over time. Various factors increase the risk of someone developing dementia. Age, genes, health and lifestyle all play a part.

There are many different types of dementia. The most common types are:

1. **Alzheimer's disease** is the most common type of dementia in older people in Ireland. Alzheimer's can also affect younger adults (aged 30-65) but this is rarer. Alzheimer's causes changes in the structure of the brain, due to a build-up of abnormal clumps of proteins. This interferes with how the brain works.

Alzheimer's symptoms tend to develop gradually over several years. Early symptoms include; difficulty remembering recent events while having a good memory for past events, having trouble concentrating, planning or organising and difficulty finding the right words.

2. **Vascular dementia** is the second most common type of dementia and it occurs when the blood supply to the brain is restricted because of blood vessel disease or as a result of a stroke or series of mini strokes which often go unnoticed and are called Trans Ischemic Attacks (TIAs).

Symptoms of vascular dementia depend on the area of the brain that has been affected. Language, reading, writing and communication can be affected. Memory problems may not be present initially, but may occur later.

3. **Dementia with Lewy Bodies (DLB)** is caused by a build-up of abnormal proteins that cause cell damage. Dementia with Lewy bodies is often associated with Parkinson's disease and shares similar symptoms. Muscle movement is affected causing difficulty with balance leading to frequent falls. Other symptoms include muscle rigidity and hallucinations. Memory is often less affected than with other types of dementia, but somebody with DLB might experience sudden bouts of confusion. Sleep can be disrupted leading the person to fall asleep easily during the day.

4. **Frontotemporal Dementia (FTD)** is more common in younger people (45-65) but can also develop in older individuals. It occurs when nerve cells in the brain die and the nerve pathways are damaged in the frontal and temporal lobes of the brain. Frontotemporal dementia affects a different part of the brain to Alzheimer's and therefore causes different symptoms.

Unlike other forms of dementia, it usually doesn't cause memory problems at first so it can be difficult to diagnose. Behaviour and personality changes are often the first, most notable, symptom and for this reason it can often be mistaken for depression at first. Difficulties with language (slow, hesitant speech) or vocabulary (trouble remembering everyday words) is another early sign that something is wrong.

5. **Young Onset Dementia** is when a person develops any type of dementia before the age of 65. It can be difficult to diagnose as doctors don't usually suspect dementia in younger people. Genetics may have a role in its development, but it is important to point out that not all cases of young onset dementia are thought to be inherited. Symptoms are similar to those experienced by people over the age of 65.

Everybody experiences dementia differently. Also, different types of dementia can affect people differently. Some common symptoms are:

- **Memory Loss:**

- Difficulty remembering recent events
- Misplacing items such as keys, wallet, glasses
- Forgetting appointments
- Problems with Language
- Difficulty finding the right word
- Taking longer to process information
- Finding it difficult to keep up with conversations especially when in a crowd

- **Difficulty with planning and organising**

- Finding it harder to make decisions or solve problems
- Taking longer to complete familiar tasks

- **Problems with attention**

- Easily distracted
- Finding it hard to concentrate, for example when reading a book
- Being confused about time and place
- Not knowing the time, day or date
- Getting disorientated or lost even in familiar places

- **Visuospatial difficulties**

- Difficulty judging distances
- Difficulty locating objects in the environment
- Misinterpreting information from the environment

Treatment

There is currently no cure for Dementia. Treatment includes both drug and non-drug approaches, looking after other medical conditions and making changes to your lifestyle. With a combination of these, it is possible to live well with dementia for many years.

Medication

Drug treatment can help lessen symptoms for a while. The drugs that are available are:

1. **Donepezil**
2. **Rivastigmine**
3. **Galantamine**

These drugs are licensed to treat mild to moderate Alzheimer's disease but are also used to treat some of the other forms of dementia. They work in a similar way, by increasing the availability of acetylcholine a chemical which helps messages to travel around the brain. The benefits can include reduced anxiety and better motivation, memory, concentration and daily living skills.

Some people experience loss of appetite, nausea or vomiting and diarrhoea initially after starting to take them but this usually resolves. Some people also report experiencing vivid dreams and sleep disturbance. If symptoms persist discuss with your doctor as you might be able to try one of the others.

4. **Memantine**

Memantine works by protecting nerve cells from the effects of a chemical in the brain which in high levels can be harmful.

Memantine is licensed to treat moderate to severe Alzheimer's disease but is often used to treat other forms of dementia. It is usually added in with one of the other drugs at a later stage or it may be used alone if you are unable to take any of the other drugs. It is usually well tolerated, but can still cause dizziness, headaches, tiredness, raised blood pressure and constipation. Should you experience these symptoms talk to your doctor.

Drug treatment isn't the only way to treat or manage the symptoms of dementia. Read sections four, five and six for more information on **non-drug management**.



SECTION 4

Staying Healthy and Living Well

Problems can seem worse if you are feeling stressed, worried or ill. If you can keep physically, mentally and socially active it will help you maintain memory, skills and self-confidence.

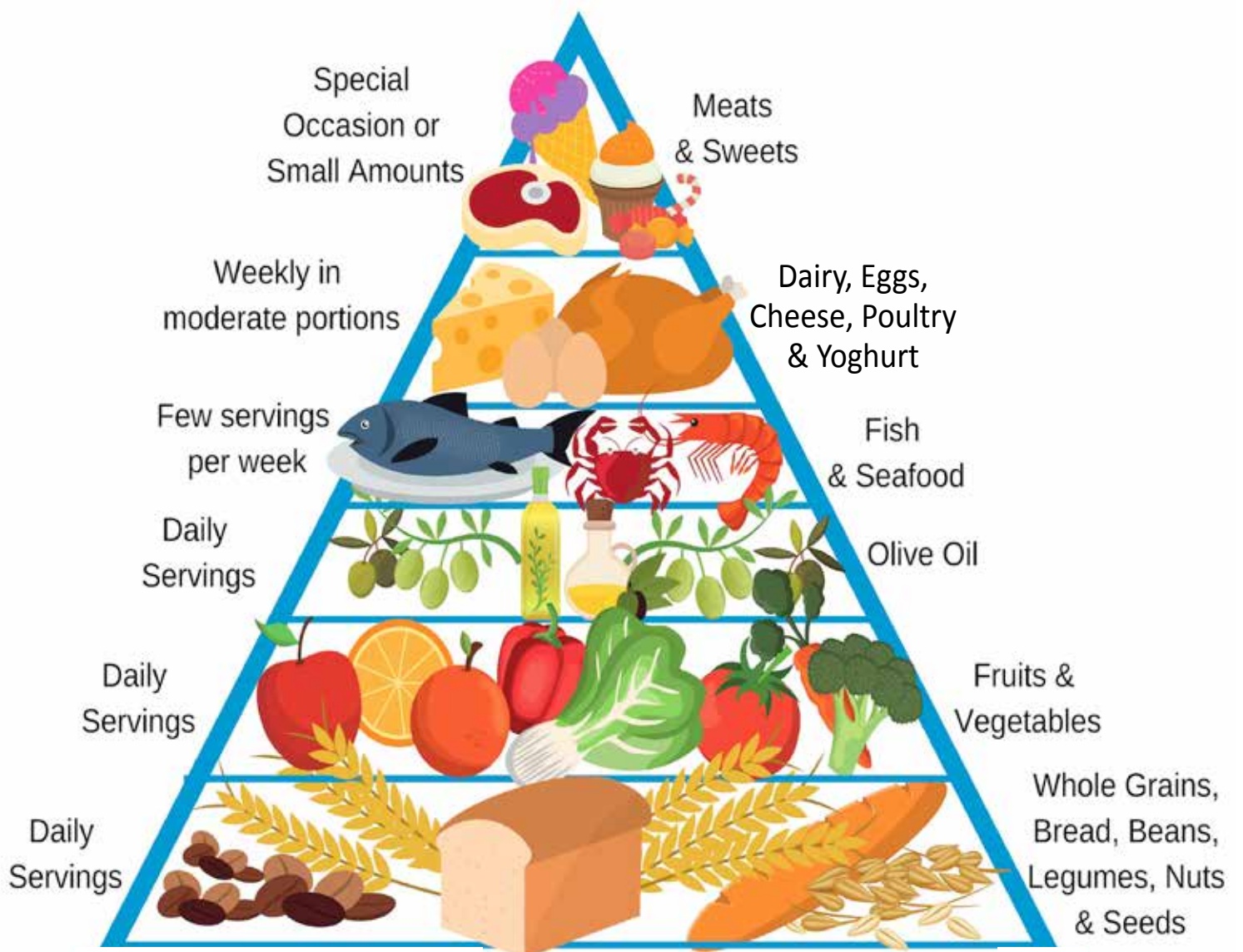
Physical Health & Mental Health

- **Pay attention to your diet:** The Mediterranean diet has become popular because people show low rate of heart disease, chronic disease, and obesity. Research has also shown that sticking to the diet more strictly might be associated with slower rates of decline in memory and thinking. Adopting a Mediterranean diet includes consuming fruit, vegetables, whole grains, nuts and fish and cutting down on red meat. See the food pyramid on page 26 for recommended daily intake advice.
- **Vegetables & Fruits:** This group includes tinned and frozen, as well as fresh fruit and vegetables. Antioxidants found in fruit and vegetables act against stress and inflammation and may help protect the brain against damage to the brain associated with dementia.
- **Meat and protein:** This group includes meat, chicken, fish, dairy products, eggs, beans and lentils. Protein is essential for maintaining muscle strength and for growth and repair of all tissues, including the immune system. Eating more oily fish such as mackerel, tuna, herring, and salmon, which is high in omega 3 is good for your brain health. If you don't eat much fish you could use fish oil supplements that contain omega 3.

- **Bread, cereals, potatoes, rice, pasta:** These foods give us energy. Some people with dementia can feel increasingly tired as the day progresses, so including some of these foods in your daily diet can help.
- **Milk and dairy:** this group includes milk, cheese, yogurt. They give us calcium for strong bones and teeth. Some recent research has also found that eating moderate amounts of dairy products seem to have some potential to slow cognitive decline. See food pyramid page 26.
- **Nuts:** nuts (walnuts, pecan nuts, pine nuts) contain healthy fats, fibre and antioxidants, and can help lower bad cholesterol and reduce the risk of heart disease. Nuts are also a good snack for brain health.
- **Olive oil:** researchers found people who use olive oil as their primary oil at home saw greater protection against cognitive decline.
- **Keep the brain hydrated:** since our bodies need water to function, not drinking enough of it prevents us from functioning at our best. Symptoms of low fluid intake include headaches, loss of concentration and drowsiness which can worsen memory symptoms. Drink six to eight glasses of fluids a day.
- **Smoking and Alcohol:** are known to be harmful for our brains. If you smoke, try to give them up or at the least cut down. Likewise if you drink alcohol, drink only in moderation. Consult your GP as it may not be advisable to drink alcohol when taking some medications.

Mediterranean Diet

Food pyramid with recommended daily intake



Stay active

Physical exercise is an important part of a healthy lifestyle, contributing to general fitness, muscle control and coordination, and to a sense of wellbeing. Physical exercise is also essential for maintaining adequate blood flow to the brain. Try to do some exercise at least five days a week for 30 minutes each time. For example, a brisk walk, dancing, jogging, cycling, or even pushing a lawnmower. Walking on a treadmill or using an exercise bike are also options. If you have any conditions that may affect your ability to do any of the above consider other options such as chair yoga or consult your GP for advice.

Keeping your brain active may help you retain memory and skills longer. Challenge yourself a little. Try learning a new hobby. Play cards such as 25 or bridge. Do puzzles or quizzes. There are many apps available which you can download to your phone or laptop.

Stay connected

Just ten minutes of social interaction can enhance your brain performance. It's important to stay in touch with people who matter to you as they can be a great support. You may also have opportunities to make new friends. For instance, find out what activities, group or clubs are available in your local area that might interest you. For example try joining the local choir, walking club, exercise class or yoga club. Consider volunteering (contact the Tipperary Volunteer Centre for more information at 062-64775). Research has shown that those with the most social interaction in their community experience the slowest rate of memory decline. Ask the nurses in the Living well with Dementia Service who may be able to provide you with more information about local activities. Most important of all choose an activity you enjoy and stick with it.

Find ways to deal with stress and worry

It is common for people to become worried when their memory lets them down. Learning to keep stress on a short leash will not only benefit your physical health but also your brain fitness and overall memory performance. Often our minds can be mobbed by worries and we can find it difficult to

focus on the task at hand. By focusing on the present moment, concentrating on what is taking place right here, right now, we can shrug off such worries. It may sound simple but it can take getting used to. Rooting awareness in the body, such as feeling the soles of your feet while walking, or focusing on breathing in and out can tie you closer to the present moment and stop the mind from wandering.

Consider attending a mindfulness course, or availing of some relaxation therapies if feeling overwhelmed or stressed. Exercise can reduce stress by releasing endorphins, the body's natural happy chemicals. Getting a good night's sleep energises you, improves your mood and your immune system. Don't forget that talking about your feelings with somebody you trust can be the best therapy.

Tips to help if you have trouble sleeping:

- Try to sleep and wake at consistent times. Set the alarm for the same time every morning and get up when it goes off. Do this whether or not you have had a good night's sleep. It will help your body develop a regular sleep pattern.
- Try to get outside more during daylight. Get some exercise but try not to exercise up to two hours before going to bed.
- Naps can be a great energy booster. If you do need one try to have it early in the afternoon and limit to no more than 30 minutes.
- Be careful with caffeine. Caffeine keeps you awake and alert, and stays in the body for up 8 hours. Avoid tea and coffee from lunchtime onwards or try caffeine free drinks.
- Avoid eating a heavy meal in the evening as digesting a meal can keep you awake or drinking too much fluid can cause you to wake up to go to the toilet.
- Don't drink alcohol before going to bed. Alcohol can definitely make you sleepy, but it can also interfere with sleep, so that you never get proper deep sleep.
- Avoid looking at your phone or computer for at least an hour before bed and keep your actual bedroom as dark as possible. Use blackout blinds to darken the room.
- Create a bedtime ritual. For example, every night before going to bed, do something that relaxes you.

SECTION 5

Practical Strategies & Assistive Technologies to assist memory

– What will make things
more manageable day to day

Practical Strategies to Support Memory and Engagement

Habits & Routines are done each day without much effort and thought, such as brushing your teeth and getting dressed. Habits and Routines can be a great support in everyday living when you are experiencing memory problems.

New habits and routines can be created to support your memory and engagement. This can take some **time and effort** to establish but once successfully created can be a great benefit to you in your daily life.

The following section outlines some strategies that can support you live independently day to day. Please note that it is very important for family to support the establishment of these strategies and to be mindful that people with memory problems may need more time to become used to something new; prompting and supporting is very important to ensure a strategy or piece of assistive technology is used successfully. For some people this may take a week and others it may be a month, it will vary for everyone.

**You will
need support to
set up a new routine
and habit**

**If family are
not there every day
consider sticking a
post-it somewhere you
will see it to remind you.**

“ Think of the person that always hung their keys up in the same spot when they came in, they will likely not experience a problem with finding their keys as they automatically and without thinking put them in the same place. ”

Using a White/Cork Board

Using a white board can be a great asset in keeping track of events coming up e.g. appointments, lunches, concerts etc. Using the cork board can be helpful for pinning up important letters/bills, a monthly calendar, or to do list. Supports like this will alleviate pressures to remember upcoming events and prevent missing appointments.



Consider the following if getting a white/cork board:

- Keep it in a space often used such as the kitchen; create the habit of using it daily so in the future it will become part of your routine
- Hang it up on the wall, leaving it leaning against the wall or flat on the surface will reduce the continuous effective use of it
- Consider how you write on the white board – for some people too much information can be cluttered and hard to follow. Clear and concise writing is best.
- Keep a section for the everyday or weekly chores e.g. at the bottom of the board in a red colour marker write the day for bins
- A calendar can be useful on the board side and can allow you to see the month ahead and jot in future appointments.
- A checklist may also be useful on the board e.g. medication, before leaving the house, or before bed. Checklists can be very useful for ensuring you don't forget important tasks.



An Orientation Clock



A clock that will automatically change day and date is a very useful support for people with memory problems. Forgetting or mistaking the day is a common concern for people with dementia and can have a negative impact on your day. Consider the following if thinking of getting an orientation clock:

- Keep in a visual space – this tends to be the kitchen for most people. The clock should be visually accessible throughout the day
- Use as part of an orientation system e.g. keep with a white/cork board or your diary
- If you are asking what day is it regularly then family should direct you to the clock to ensure it becomes a habit for you to check
- There are a range of orientation clocks available and these can be viewed at the Memory Technology Library in Clonmel to help you decide which will work best for you.
- Some clocks are digital and have daily reminders to prompt you e.g. medication reminder.

Please make an appointment with the occupational therapist in the Memory Technology Library in Clonmel to demonstrate assistive technologies and discuss practical strategies.

052 61 77080

Keeping a Diary

Keeping a diary to stay on top of everyday obligations, events, birthdays, appointments and social arrangements can be a great support to stay engaged and not miss appointments. Consider the following if you are starting to keep a diary:

- **Where will the diary be kept?** Keeping it in the same place is a good habit to get into; this will be protective for you in the future and will support you using it regularly and reduce misplacing the diary.
- **What size diary and layout will work best for you?** Some diaries have the entire week across two pages which can be useful for some people to see what is ahead, however it might be clearer and easier to follow having a full page per day.
- At the beginning it will be important that **you are prompted to using the diary everyday** so it can become habitual to you in the future.
- **It is best to write in the known events first** such as bin days, birthdays and anniversaries.
- **Clear and concise writing** is important to use so it will be clear to you when the event comes up. If others are writing into the diary to remind you of dates then they must be clear and concise also.

Using a Pocket Notebook

For your bag or pocket a small notebook with pencil attached can be worthwhile having. Consider the following for use:

- Jotting in a line or two to remind you of a conversation you had while you were out.
- If you receive a call or meet someone and you have made arrangements.



- A to do list
- Where you parked your car
- When you get home check the notepad and transfer relevant information into your diary.

“

It is good to challenge yourself in the evenings to jot down what happened throughout the day and to read through this the following day.

”

Using a Journal

Using a journal is another helpful support to retrieve information from events in the day.

If someone has told you something that is important and meaningful, write this into your journal, and use the pocket notebook to help you remember.

A journal is personal and you should use as you desire. The journal can be a useful resource to look back on if you are trying to recall events. Consider the following:

- Always put the day and date at the top of the journal
- Write the necessary information in a format that suits you and will promote continuous use such as the **WH & H Format**

WH & H Format

Who?

What?

When?

Where?

Why?

How?

Other Helpful Tips

Post-it Notes

These can be simple and handy to remind you of things to do e.g. place on locker near bed or at washing machine or anywhere you need a quick reminder to do something



Telephone Note Pad

Keep a note pad near the phone so that all important calls can be noted. It may also be useful if arrangements have been made over the phone to jot into the notepad.

Timers

These are useful in the kitchen to remind you of something to check in the oven

Checklists

Checklists are a very useful strategy to support safety and independence, a checklist might be placed on the back of the door to remind you of items to bring with you when going out or you may have a checklist for night time to go through when locking up the house before bed.

Organising Space

Adapting your environment to be more organised can be helpful; **A place for everything and everything in its place!** Encouraging items to be placed in the same locations i.e. post/bills, keys, chargers, remotes etc. Forming this habit earlier allows it to stick and may avoid misplacing such items in the future.



Assistive Technologies to Support Engagement and Independence

There is a wide range of **Assistive Technologies (AT)** available to support memory problems. Some of these are listed below but you can learn more about these at the Memory Technology Library.

Orientation Clocks

As mentioned in the strategies section orientation clocks are supportive for continued independence in everyday activities. For many people with dementia the day can be difficult to recall and cause a negative impact to your day. For example, missing an appointment is likely to happen if you do not know what day it is.

The following are some of the orientation clocks available:

Grayson Desktop Clock

- Helps to keep you orientated to the correct day and date
- Requires no adjustment at the end of the calendar month including a leap year
- Can be wall mounted
- The black and white provides a good colour contrast



Digital Calendar Clock

There are a range of digital clocks available:

- Different viewing options available i.e. day-date-time, or day-time of day
- Some digital clocks come with 20 pre-programmed alarms e.g. remember to take your medication



Key Finders

If you are regularly looking for your keys, wallet or handbag then a key finder might help reduce this. There are different types of key finders please see the two below:

Object Locator Key Finder

- Helps you locate different objects around the house
- Remote control activates the keyring beeper
- Ideal for helping you find your keys or bags
- Supplied with five wireless keyring beepers



Chipolo Key Finder

- **Attach** Chipolo to anything you don't want to lose and connect it to the Chipolo app.
- **Ring** Chipolo from the app or double press it to ring your phone. Even if it's on silent.
- **Find** your missing items. The app remembers when and where you last had them.



Medication Reminders

These can be programmed to alarm at the time when you need to take your medication. There are a range of medication reminders and these will not be suitable for everyone. To learn more please visit the Memory Technology Library. Two types are below for you to view.

Automatic Pill Dispenser

- At the pre-programmed times, the dispenser rotates, the alarm signal is heard, and the correct dosage comes into view through the opening in the lid.
- Dispense pills by tipping into your hand or a suitable container.
- There are 28 compartments



Tabtime Super 8 Pillbox

- Up to 8 daily alarms at whatever times you require
- Or if only taking tablets once a day this can be filled and used for the 8 days
- Flashing Red LED light on the lid will flash at the same time as the alarm.
- Small and light that can fit into your bag or pocket.



Please be aware that assistive technologies must be monitored by someone. Please consider the following:

- Who will set up the assistive technology?
- Does it require a mains supply to operate? If so might this be plugged out at night time?
- Does it require batteries? If so who will be responsible to check and change? If a battery leaks it may ruin the assistive technology.
- Does the piece of assistive technology make a noise to alert you? Consider this at home, would it bother you?
- Consider a piece of assistive technology that is monitoring you, for example, GPS tracking, a motion sensor and telecare. These can be very supportive and allow continued engagement and safety however they can infringe on your rights to privacy and should be used appropriately and with your consent. Discuss this with your family now because in the future it is important that your wants and needs are heard and respected please (*please see page 48*).

For more information on Assistive Technologies please visit the Memory Technology Library section on:

www.southtipperarydementia.ie

Also available from the Alzheimers Society is the booklet
“Practical Steps to Support Independence”
which you will find on their website:

www.alzheimer.ie



SECTION 6

Planning

- What will make things easier in the long term

Planning

Here are some of the things that can make it easier for you in the long term. Tackling these issues early can save a lot of hassle later on.

“

...the nurse advised me to do the will, talk to my solicitor about an EPA, and my GP about the driving, you know all that stuff and I did it straight away because if I waited I mightn't have bothered. I felt relieved to have all those things sorted. I could get on with things because all that stuff wasn't hanging over my head. It was a huge relief to get it all done and out of the way for me and my family

”

Finances

1. If you are still working, make sure to seek professional advice before making any decision about your job. Dementia is a disability and there are laws to protect you. The employer is obliged to take 'appropriate measures' to enable anybody with a disability to carry out their work on an equal footing with others.
2. Claim any social welfare benefits that you may be entitled to such as Disability Allowance, Illness Benefit, Invalidity Pension or any other entitlements. For more information contact the Department of Social Protection or Citizens Information (**see page 54 for contact details**).

3. If you are receiving a pension but are unable to collect it, you can appoint an 'agent' to collect it for you. You can make enquires at your local post office. It is important to note also that all social welfare payments including pension payments can be paid directly into your bank account.
4. If you are still working or have a mortgage check any insurance, income protection or critical illness policies you may have to see if they cover Alzheimer's disease and the other dementias. Some policies pay out early on a diagnosis of conditions such as dementia.
5. If you are experiencing financial problems you could contact MABS (Money Advice and Budgeting Service). MABS is the State's money advice service, and helps guide people through dealing with problem debt **(see page 55 for contact details)**.

Bank Accounts and Utility Bills

1. If your personal finances are complex you may want to simplify or streamline your affairs. This could mean having one or two bank accounts instead of several. If you use the internet it may be possible to pay bills and manage your bills from home. You could also set up 'direct debits' to pay regular bills such as ESB, phone, gas.
2. Write a list with details of your bank accounts, savings or other assets. Keep the list in a safe place. Tell at least one person you trust where the list is, this could be a family member, your solicitor or both.

3. Arrange to have bills paid from your bank account when it most suits you. For example you could arrange direct debits to be paid after your wages or pension have been lodged so as to ensure there are sufficient funds in your account. Once bills are paid you then know how much money is available to you for the rest of the week or month.
4. Utility companies, such as Bord Gais and the ESB are reluctant to speak to people not named on the bill so put your utility bills in joint names if possible.

Apply for a medical card

1. Apply for a medical card or if your income exceeds the limit you may still qualify for a discretionary medical card if you can show that you would experience financial hardship without one. Apply first for a medical card and if refused reapply requesting to be assessed for a discretionary medical card.
2. If you apply for a medical card and fail to qualify you are automatically assessed for a GP visit card. This entitles you to free visits to your GP. The GP visit card is automatically available to everyone aged over 70 without an income test. If you are aged under 70, eligibility for the GP visit card is means tested. That is, your income is assessed by the HSE as part of the application process.
3. If you have neither a medical card, nor a GP visit card and don't qualify for the Long Term Illness Scheme, you can use the Drugs Payment Scheme to limit your expenses on prescription drugs.

Wills and Enduring Power of Attorney

1. A will is a legal document that sets out who you want to inherit your possessions, property and money (in other words your estate) when you die. When making or updating a will it is important to get legal advice. Your solicitor may seek certification from a medical practitioner with regard to ‘testamentary capacity’ before you make or update your will. As part of making your will you appoint one or two people to manage your estate. These are called ‘executors’. Once you have your will made it is possible to review it and make changes if you wish. A will only takes effect after you die. If you die without making a will, the law sets out who may inherit from you and in what order. It is important to make a will so that you can choose what happens to your estate after you die.
2. If a person becomes mentally incapacitated, all of their assets and property are normally frozen and cannot be used or accessed by anyone else unless they are jointly owned, or someone has created an enduring power of attorney (EPA) to deal with their property or affairs. Many people have enduring powers of attorney regardless of any illness or diagnosis. An EPA is a legal document that sets out who you would like to manage legal, financial and certain personal care decisions for you, if you reach a point where you cannot make these decisions yourself. Your Attorney can be people such as your spouse, partner, parent, sibling or friend. The choice of Attorney is a personal matter, but thought needs to be given to the nomination. Talk to your solicitor about whether you should set up an EPA. When setting up an EPA you will need a statement from your doctor confirming you understand the effect of creating the enduring power of attorney.

“

**There is no set fee for this work so shop around as prices can vary significantly between solicitors.
Visit your local Citizens Information Centre
or Free Legal Advice Centre for more advice.**

”

Driving

Your doctor is best positioned to advise you whether to continue driving or whether to stop. Many people continue to drive successfully after a diagnosis of dementia. If your GP has concerns about your driving he/she may ask you to complete an 'on road' driving assessment. Normally, for an 'on-road' assessment, an assessor accompanies you as you drive around familiar routes in your local area. However, some might require you to attend a driving centre. Prices also vary, so ask about both when making an enquiry.

The assessor will focus on your ability to drive safely and competently. They will then write a report stating either you can continue to drive, drive with restrictions or that you need to stop driving.

There are several assessors in the Munster region including:

- **Southern Mobility:**
Tomas O'Callaghan Tel. 087 9304 335 / 021 4355 411
- **Irish Wheelchair Association (IWA)**
Tel. 045 893094 (nationwide service)
- **Southeast Mobility:**
Michelle Sheehan Tel. 087-9908115 / 051-397952
- **Results Driving Assessment Services:**
Tim O'Donoghue Tel. 069 61999 / 087 2633599

It is also a good idea to ask a family member to sit into the car from time to time to observe how you are doing. At some point you will have to stop driving when it is no longer safe to continue.

1. All car insurance policies require that you tell the insurance company of a change to your health status. This includes a diagnosis of dementia. If you do not do this, your insurance policy may not be valid. Your insurance company should not withdraw your insurance or automatically increase the cost if your doctor states that you can continue driving safely.
2. You must notify the National Driving Licence Service. You will have to visit your local centre with:
 - a. Your current driving licence
 - b. Proof of you PPS Number
 - c. A completed driving licence application form (D401)
 - d. A driving licence medical report completed by your doctor (D501). Your doctor may ask you to take an on-road driving assessment which is carried out by a qualified driving assessor (*see page 46*).



Healthcare Needs

It can be hard to think about what might happen as your dementia progresses. Taking early steps to plan your care means that your family and your healthcare team can be made aware of your wishes and preferences.

Here are some questions to consider;

- Who would you like included in discussions about your medical condition and discussions about your health and medical care?
- What would you like to happen in relation to the use of certain medical or surgical interventions or treatments?
- Are there cultural or religious preferences you would like healthcare staff to know about when taking care of you?
- Who would you like to visit you or not visit you if you were in hospital?
- If you have a partner and you are not married to each other, it is important to express your wishes about their involvement as your dementia progresses.

Consider completing an **Advance Directive** which can document your preferences with regard to the questions raised above and capture any other relevant information such as future living arrangements etc.

The **Think Ahead** form published by the Irish Hospice Foundation provides a guide to members of the public to help you discuss and record your preferences in the event of an emergency, serious illness, or death.

Details about your emergency contacts, health information, legal information, financial affairs and wishes for care before and after death can be documented on the form and shared with family and loved ones

(see page 57 for website details).

SECTION 7

Supports and Services

You do not have to face dementia on your own. There are lots of people who can support you. Here are some of the services and supports available locally.

Healthcare Professionals

GP: For most people concerned about their memory their first point of contact is their GP. The GP undertakes assessment and can refer to specialist (hospital consultant, psychiatry) and allied health services (occupational therapist, physiotherapist, dietician, speech & language therapist). Following a diagnosis of dementia the GP may prescribe medication and can also provide general advice and information.

Memory Clinic: The memory clinic is based in St Patrick's Hospital, Cashel. It is a specialist assessment and diagnostic service. The consultant/advanced nurse practitioner will discuss your diagnosis and the steps you should take. You may also be referred to the Living well with Dementia Service for more information and where appropriate to participate in one of their post diagnostic programmes.

PHN: The Public Health Nurse is based in the local health centre or primary care unit. They provide nursing services to people who have a medical card. (However, in many/most areas PHNs may provide nursing services to non-medical card holders subject to the level of available resources in the local area). They are able to offer advice and information and can refer to other healthcare professionals including the GP, allied healthcare services and services such as the Home Support Service, Meals on Wheels and day care services.

Pharmacists: Your pharmacist can also be a support and it may be helpful to build a relationship with one particular pharmacist.

Dementia Specific Services and Supports in South Tipperary

1. **Living Well with Dementia South Tipperary Service**

provides a point of contact where people diagnosed with dementia and their families can access information and advice. The team consists of 2 dementia nurse specialists and an occupational therapist. The service which is fully funded by the HSE and managed by Family Carers Ireland is based in the **Memory Technology Library on the grounds of South Tipperary General Hospital.**

You can make an appointment to visit the Memory Technology Library and/or arrange for a nurse to call to your home to answer any queries or discuss any concerns you or your family may have. She can also advise regarding managing symptoms, sign posting services and provide more information and clarification about topics discussed in this handbook. The occupational therapist can advise you with regard to practical strategies that can compensate for your everyday memory difficulties. She can also advise with regard to assistive technologies which are available to view in the Memory Technology Library.

Other services provided by the Living Well with Dementia Service include:

- Memory Rehabilitation Programme for people newly diagnosed and living with early stage dementia & Psychoeducation Programme for people with mild/moderate dementia. These programmes aim to teach techniques to compensate for everyday memory difficulties. An important aspect of these programmes is the advice and support provided to you and your family by the living well with dementia team.
- Two day education programme for healthcare staff and family members.
- Dementia Support Worker Service – some people lose confidence after a diagnosis of dementia and can find it difficult to engage socially or participate in local community activities. Staying socially engaged can help slow the symptoms of dementia. The Living Well with Dementia Service may be able to provide a support worker for a period of time to support your participation in local activities such as sporting activities, walking, art groups or other activities important to you.

Website:

www.southtipperarydementia.ie

Email:

livingwellwithdementia@hse.ie

Contact: Emma O'Brien OT, Memory Technology Library

052 6177080

or Anne Quinn & Mary Ryan Dementia Nurse Specialists

087 0550050

2. Let's Talk Tipperary Memory Support Group

- is for people newly diagnosed and living with 'early stage dementia'. It was set up by a group of people with dementia so that people can meet and talk to people who are in a similar position to themselves.

The group is supported by the Living Well with Dementia Service. The group meets every Wednesday in Place 4 U Café Morton Street, Clonmel between 10am and 12.30pm. From time to time information talks and some programmes e.g. 'mindfulness' are organised by the group. Contact Anne/Mary at 087 0550050 for more information if interested in attending.

3. Dementia Advisor Service

- provided by the Alzheimer Society of Ireland (ASI). Like the Living Well with Dementia Service above the Dementia Advisor Service provides locally based, one-to-one information, signposting, and emotional support. The Dementia Advisor can meet you in your own home or at an agreed location. The Dementia Advisor for the Munster region is Amy Murphy. Amy can be contacted at 086 7812217. For other services provided by the ASI in South Tipperary contact Catherine Bartels at 052 6176775 or 086 0490548.

4. National Dementia Specific Services and Supports

- **Alzheimer Society Ireland National Helpline:** The Alzheimer Society of Ireland's National Helpline is a confidential information and support service for people with dementia and their families. The Helpline service aims to provide accurate, up-date, accessible and relevant information and emotional support to service users. The Helpline is open 6 days a week. Call **1800 341 341** or email **helpline@alzheimer.ie**
- **Understand Together:** Understand Together is a public support, awareness and information campaign. The website features a service finder detailing county-by-county the dementia supports and services available.

Website: **www.understandtogether.ie**



Other useful services and organisations

Family Carers Ireland

The Carers Association is the National Voluntary Organisation for Family Carer's. Services provided by the Carers Association in Sarsfield Street include: information on all social welfare entitlements; training for carers; monthly support group meetings; home respite services to aid family carers. The local area office is based in 8 Sarsfield Street, Clonmel.

Tel: **052 6170454 / 6170455**
Fax: **052 6170456**
Mobile: **086 8051061**
Email: **carersclonmel@carersireland.com**
Website: **www.carersireland.com**

Citizens Information Centre

The Citizens Information Centre provides comprehensive information on public services and on the entitlements of citizens in Ireland. Information is gathered from various government departments and agencies, and is presented in an easy-to-understand way.

Clonmel: **Tel. 0761 07 6460**
Tipperary: **Tel. 0761 07 6540**
Website: **www.citizensinformation.ie/en**

FLAC

Free Legal Advice Centre – Volunteer lawyers provide confidential, basic legal advice for free and in person across all areas of law. They operate in co-operation and involvement with Citizens Information Centres throughout the country.

Tel: **17890 350 250**
Website: **www.flac.ie**

Legal Aid Board

The Legal Aid Board provides legal aid and advice on matters of civil law to persons unable to fund such services from their own resources.

Tel: **1890 615200**
Website: **www.legalaidboard.ie/en**

MABS

Money Advice and Budgeting Service is the State's money advice service.

Clonmel: **0761 07 2750**
Tipperary: **0761 07 2130**
Carrick-on-Suir: **0761 07 2810**
Cahir: **052 7443066**

IDWG

The **Irish Dementia Working Group** is an advocacy group of people who have been diagnosed with dementia. The group is an independent campaigning voice for people living with dementia with members throughout Ireland. The group meet to share experiences and highlight issues that are important to them. The group is supported by The ASI and their work is overseen by a Steering Group comprised of people living with dementia. The southern group meets in Mitchelstown.

Email: **advocacy@alzheimer.ie**

SAGE

Many people face challenges to their independence due to physical or mental illness, intellectual, physical or sensory disability, lack of family and community supports or an inability to access public services that meet their needs. Through support and advocacy the will and preference of a person can be heard and acted on. Sage was established as an independent support and advocacy service for vulnerable adults, older people and healthcare patients. Martina Durkan is a patient advocate in Tipperary South.

Tel: **085 8623585**
Email: **martina.durkan@sageadvocacy.ie**
Website: **www.sageadvocacy.ie**

Useful websites

Living Well with Dementia South Tipperary/Memory Technology Library

The website provides information about dementia and supports available. You can also get information about products available for viewing in the Memory Technology Library.

Email: livingwellwithdementia@hse.ie

Website: www.southtipperarydementia.ie

Alzheimer Society of Ireland

The website provides information and practical steps to help you and your family to live well with dementia. You can also view video clips of people talking about their own experiences.

Website: www.alzheimer.ie

Hello Brain

This website provides easy-to-understand scientific information about brain health.

Email: hellobrain@tcd.ie

Website: hellobrain.eu/en/

DSIDC

Dementia Services Information and Development Centre, St James's Hospital, Dublin is a National Centre for excellence in dementia and is committed to best practice in all aspects of dementia care.

Email: dsidc@stjames.ie

Website: www.dementia.ie

IHF

Irish Hospice Foundation: Think Ahead is an Irish Hospice Foundation programme. It provides a guide to members of the public to help you discuss and record your preferences in the event of an emergency, serious illness, or death. The programme is an idea that came to life through feedback from people like you — people from all walks of life, all ages and all levels of health across the country.

Website: hospicefoundation.ie/programmes/public-awareness/think-ahead/

Conclusion

The key to managing a diagnosis of dementia is informing yourself and taking the necessary steps as soon as possible after your diagnosis that will make things easier for you not only in the short term but also in the longer term. It is about living your life as independently as you can one day at a time reassured that you have things in place for the future. Don't be afraid to let others help when you need it. Family, friends and when required formal services can be a great source of support in helping you to live well with dementia. Keep this book so that you can refer to it for information.

You can also contact the Living Well with Dementia Service anytime Monday to Friday between 9am and 5pm.



What to do following a diagnosis of dementia

CHECKLIST

- ☒ **Acknowledge your feelings and take care of your emotional needs**
Talk to the people closest to you
- ☒ **Learn about dementia. Find out what services and supports are available.** Contact the Living Well with Dementia Service
- ☒ **Make the changes that can help you stay healthy and may lessen symptoms**
 - Eat a healthy diet
 - Stay active – some daily physical and mental exercise
 - Stay social – meeting friends or join a club/group
- ☒ **Make the changes that can help you in the short term :**
 - Find out about practical strategies and assistive technologies that can compensate for everyday memory difficulties
- ☒ **Make the changes that can help you in the long term:**
 - Organise your bills and finances
 - Talk to your solicitor about whether you should set up an EPA
 - Talk to your solicitor about making a will
 - Talk to your GP and family about your care needs and preferences
- ☒ **If you are driving talk to your GP who is best positioned to advise you on whether to continue or stop. He might ask you to complete an 'on road driving assessment'. If continuing to drive you must:**
 - Tell your insurance company
 - Notify the National Driving Licence Service

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Living Well with Dementia South Tipperary
www.southtippdementia.ie