

DEMENTIA-DIAGNOSIS-WHAT NEXT? PURPLE ANGEL DEMENTIA CAMPAIGN



This booklet has been published out of necessity, so many people have told us even after all the years of campaigning things still haven't changed that much, so, being a Dementia charity that NEVER gives up, we are going to try all over again. Here are our TOP TIPS of what to do before your diagnosis, and after, with a few helpful phone numbers there as well, because people are THERE To help, but if nobody tells you this how do you know? All contents written by carers and those living with dementia and in PLAIN ENGLISH, simple it may be, but INFORMATIVE it definitely is.

Norrms Mc Namara, Living With Lewy Bodys type dementia, Founder of Global
Purple Angel dementia campaign
Charity number 1189616 Website <https://purpleangel-global.com/>



DO YOU THINK YOU MAY BE HAVING MEMORY PROBLEMS?

If you or someone you know thinks you're having memory problems, please make an appointment with your Dr, GP, straight away. No matter what age you are, please remember dementia can strike at any age to anyone, there is a type of dementia which affects children so please don't be fooled into thinking you're too young no matter what age.

WHAT TO DO

1. Make a DOUBLE Appointment with your GP, you are fully entitled too and believe me you will need that time, 10 mins just doesn't cut it or long enough, as you need to be heard.
2. Before you sit down with the Dr, please write down all your questions before you go in and make sure they answer each one, don't be afraid to interrupt and ask for clarity, so important you know as many of the facts as possible.
3. Don't be afraid to ask the questions nobody usually does, Incontinence, Hallucinations, night terrors. The most asked question is usually HOW LONG? And quite understandable, but please understand nobody really knows the answer, I have had this disease 15 years and there are people all over the world have lived 20/25/years + with it, so please don't give up hope.
4. Don't be rushed, probably easier said than done but remember this is your time, they are there for you.
5. Being honest and up front with you please don't expect too much, Drs, GPs are not highly trained in dementia and is only (sadly) a small part of what they have to learn about.
6. Once you have asked your questions and are satisfied with what you have been told, you must ask "SO WHATS NEXT PLEASE??" Please ask this as you might be lucky enough to have someone quailed in dementia at your practice.

7. THIS IS SO IMPORTANT

Before you leave the surgery, practice, make a follow up appointment because I can guarantee you that you will get home, sit down and think "I wish I would have asked that? That's the time to start writing the questions down again and take them with you when you visit next time.

8. Try not to worry, there is help out there and over the next couple of pages we will show you who and how to contact

WHEN YOU GET DIAGNOSED

When you're sat there and the Dr or Consultant says to you I am sorry, but you have dementia, PLEASE PLEASE ASK WHAT KIND? WHAT TYPE?

This is so very important as there are so many different types of dementias and what medication you receive should, and I say SHOULD, depend on which type of dementia you have been diagnosed with, getting the wrong medication can cause so many problems. Also ask "Why have you come to that conclusion and no other type of dementia? The reason I mention this is very personal to me as I was diagnosed with the Alzheimer Type before being told I had been misdiagnosed and I actually had the Lewy body's type. Then ask before you leave, "WHAT NEXT" and "Have you got any leaflets, booklets, phone numbers we can read or contact both locally and nationally, please remember, at the time this has been written there is no known cure for dementia and you both need, and are entitled to as much help as you can get, if you had just been diagnosed with cancer they would be throwing information at you, dementia is no different than any other serious /terminal disease.

CHOOSING A CARE HOME - TOP TIPS

1. Arrive unannounced, you will see what it's like in real time.
2. Does it smell? Always a giveaway of bad care if it does
3. Visit at busiest times, IE Lunchtime so you can see what's on the menu and how they are coping
4. Take notice of how the residents are dressed, would you let your own parents, loved ones look like that? If so, all ok
5. check and ask the activities board, always a must as inclusion is so important
6. Last but certainly not least, ASK the care home residents what they think, not all have dementia, some are there because of other reasons

WHO TO TURN TO ??

This is advisory only, as it would depend on your situation, but please inform all members of your family, those closest to you etc. This will stop any rumours or wrong information being shared amongst them and then at least they will know, what to expect, it's the not knowing that can be the worst thing, that's why you MUST ask as many questions you can about it. Learn about it, better the devil you know, eh? Then enquire about Local memory cafes, national helplines etc, here's just a few locally and UK wide but please check out your nearest memory café, support centre Etc

Purple Angel memory café, Barton Baptist church, Happaway road, Torquay every Saturday except second Saturday of the month, 1.30pm till 3.30pm Completely FREE!!

Enquiries DONNA 07894 015293 Rachel 07984 998397.

Chadwell Centre Torbay 01803 546470

Torbay memory clinic Torbay Hospital

Tel: 01803 655602

Outpatient booking: 01803 656337

The Admiral Nurse NATIONAL Dementia Helpline is a free service that provides support for people with dementia, carers, and health and social care professionals:

Contact: Call 0800 888 6678 or email helpline@dementiauk.org

Hours: Monday–Friday 9 AM–9 PM, Saturday–Sunday 9 AM–5 PM, and bank holidays 9 AM–5 PM, except Christmas Day

MEMORY CAFÉS UK

<https://www.memorycafedirectory.com/united-kingdom/>