

PEER TO PEER RESOURCE

Work after a diagnosis of dementia

by Martin Roberston

life 
changes
trust

Introduction

Why I have written this book

My diagnosis was at 6.30 in the evening, and I was given no leaflets or advice at all. I decided, there and then, to give up work. I never went back, except for all the paperwork.

I did this because I saw, in a moment of clarity, that I could now do what I wanted, when I wanted, and if I wanted. Also, I worked in social care on the front line and realised that I could make, literally, a fatal mistake, which I could not have lived with. I was also told to stop driving, and again I saw the wisdom of this.

In hindsight, I can see that there were signs of dementia, but did not recognise them as such, because I have a rare type: Posterior Cortical Atrophy which starts at the back and affects the senses first. You can read more about it here:

<https://www.rarementiasupport.org>

Even though I never went back to work, there were still plenty of hoops to jump through. This booklet is aimed at not only assisting others to jump through the hoops, but also to decide whether to stay at work, as I realise that not everyone will be as keen as I was to stop paid work forever.

In summary, and discussed later in this resource, the hoops included; the Local Authority's Occupational Health Department, and the Department of Work and Pensions.

Work, in this context, can mean paid work, either for someone else or self-employed, as well as voluntary work – or even, as in my case, research and occasional campaigning.

If one does give up paid work and applies for certain state benefits, there are rules to follow which I will briefly discuss in Chapter 2.

Research undertaken

When writing this booklet, I carried out my own research using the internet to source academic institutions and a relevant academic paper, as well as asking via twitter and email for people to contact me to share their experiences.

I also drew on two books written by people with dementia describing their personal experiences before, during and after diagnosis – 'Somebody I Used to Know' and 'Slow Puncture'. These can be found in the resources section at the end.

Other individuals emailed me with their own experiences of how their employer dealt with the diagnosis. From this research, I was able to obtain unique insights into how individuals experienced their diagnosis and how, sometimes, they found it very hard to come to terms with the immediate and life changing problems they now faced, in particular around work, although their methods of coping are applicable even for someone who is not working.

I would like this booklet to be helpful to those with dementia, and to show them that there can be meaningful work, paid or unpaid, after a diagnosis.

Please note: this resource was written during the COVID-19 pandemic.

Chapter 1

The Diagnosis

When someone receives a diagnosis of dementia, it is usually because that person has had problems cognitively, for example, with thinking, memory and reasoning, and in my case, sensory issues.

Often the person has had difficulties in remembering things at work. In the research, one of the ways that people said they stayed on top of reminding themselves to do something, was the use of yellow post-it notes. In fact, one person said:

“Yet now I wish for just one single post-it note to tell me I still have a purpose.”

I will return to the 'post-it note' in another chapter.

However, few people who are still actively working actually expect a diagnosis of dementia, mainly because dementia is seen as a disease of older people, and not those of working age.

The majority of symptoms given to the consultants by the people I spoke to, were of memory loss, depression due to not understanding what was happening to them, and not sleeping due to worrying.

Diagnosis often came after many visits to the GP and consultant, because symptoms were put down to depression. The individual may have been given tablets and then time was allowed for the medication to work. Only when that failed – and even then not always – were further tests carried out such as MRIs.

What were people's experiences at work?

First of all, there is no legal obligation to inform your employer of a dementia diagnosis, unless you are in the Armed Services, or your work involves driving. When diagnosed, you do have a legal obligation to tell the Driver and Vehicle Licensing Agency in Swansea; www.gov.uk/government/organisations/driver-and-vehicle-licensing-agency.

"You hated letting anyone at work down."

People often put in extra hours to hide their problems from other staff: coming in early, leaving late, and even working at home, all for no extra pay. In other cases, the staff working with the person knew they were not working well, so covered up for them.

In one example, a self-employed offshore oil sub-contractor kept filling out certification forms incorrectly, but his co-workers corrected them. He did not even realise he had problems at work until after his diagnosis, when he told his manager who was also surprised, until they did their own research. By this time, the oil sub-contractor was too far down the dementia route to fully understand and he believed that he was not being given work due to a cyclical downturn.

The general impression from those that I spoke with was that most employers used the disciplinary route, which certainly did not help people with the stress involved with diagnosis. Many just gave up and left of their own accord: this is NOT a good idea. The reason this is not a good idea is that the Department of Work and Pensions (where you claim 'in work' benefits from) will look at whether you left work for a good enough reason.

Obviously, they should just accept the reason, but when claiming Employment Support Allowance you will require six months' worth of 'Get Well' notes (the new name for 'Sick Notes'). I will explain more about this process in the next chapter.

“You need someone who knows the rules to help you because the businesses don’t want to help you.”

Based on what people said, businesses, on the whole, were not interested in what the person could offer in a different role.

“...ignored the skill base I had and just didn’t care...”

One example of this is from an airline pilot who said:

“They should have recognised me as an individual, with 20 years of experience, they could have offered me a position at the ground school.”

As mentioned, these bad experiences all had a negative effect on the person with dementia, just when they were starting on a new journey and required help.

Some – very few, as already shown – received good help from their employer. One person said:

“It is a two way street with the employer and employee working together.”

In this case, the employer put in place an Occupational Health assessment, and the employee was employed in a more suitable role, with a regular assessment to keep an eye on the situation.

All this shows that informed and positive decisions about work after a dementia diagnosis are able to assist in the transition, but bad experiences make the transition so much worse.

In the next chapter we will explore in more detail best practice and what employers can do to support people to remain in work.

Chapter 2

Reasonable Adjustments

This chapter will look at best practice and what employers can, and should, do to assist individuals to stay in work. It will also look at finding new work, whether paid or unpaid, as another job might fit you better. There will be a piece at the end regarding what state benefits are available.

From the research, the size of employer does not seem to matter in terms of whether it is good at working with people with dementia or not.

“As an NHS team leader, I thought I was working in the right place to have a condition like this. But although the NHS is very good at looking after their patients, they are not so good at looking after their employees.”

However, there are plenty of examples of good practice:

“They took this advice and supported me in what I wanted to do. They gave me the opportunity, they were willing to explore possibilities, and they gave me the chance!”

With this particular employee, her employer changed her regular work place, so it was easier for her to travel, and arranged for a buddy to aid her in getting to work. They even bought voice recognition software which allowed her to carry on as much as possible.

In another case, an employee told his boss about the diagnosis, but they decided at that moment in time, there was no need for alterations. However, his role has changed along with his illness to allow him to carry on working. For instance, he now works a four day week to allow more time for rest.

“Because of this experience, he believes they {the employer} have a better understanding of how to help others with dementia in their workforce.”

What are Reasonable Adjustments?

Now that we have seen examples of where employers can make 'reasonable adjustments', we will talk more about what these can be. It will not be an exhaustive list, but will give a general impression of what is possible. The two positive examples described previously are from relatively small firms so the size of organisation should not be a concern.

Self-employment

If one is self-employed, the adjustments that are possible will be dependent on your own abilities and finances. There are actually more disabled people in self-employment (not just those with dementia) proportionately; 18%, as compared to those who are able, which is 14%. This shows that it can be done and there are grants available both from the UK Government and the Scottish Government, as well as from charities dedicated to enabling disabled people to work for themselves (grantsexpert.co.uk). Working for yourself allows you to dictate your hours and what type of work you do, as well as not having to face hidden discrimination you may encounter when working for an employer.

I would categorise family firms under self-employment. However, there is the added emotional pressure of not wanting to let your family members down. You can obviously make your own adjustments as you see fit, although you can try and make too many.

“I was left literally sweeping the yard - imagine it - running a broom around the yard of the business that my father had started...I was not going to allow myself to be humiliated like this.”

The 'post-it' note

Before I explain what adjustments employers can make, I would like to mention one that you can do yourself, which I have already touched upon. Yellow post-it notes can be used to remind yourself of important dates etc, but never use one for your computer password, as others could use it too!

On my last three working Mondays, I had to telephone IT because I had forgotten my password. I only worked four days, so after three at home I forgot it.

I would like to think that the IT department (a Local Authority) would have at some point informed my line manager of this repeated questioning, as it would have served as another warning sign something was wrong.

Best Practice

The type of work being done also makes a difference to whether adjustments are 'reasonable', or even required at all. There were no adjustments possible at my workplace as every decision and action I took could irrevocably damage the life of a client, as I was working in personal care. If one is doing a repetitive job, such as stocking shelves, adjustments might not be necessary at all.

All of these adjustments are equally relevant to making a public facing workplace 'dementia friendly', and as has been said, making somewhere suitable for people with dementia makes it better for all.

The first, obvious point to be made is that an employer has no requirement to make reasonable adjustments unless they know of your diagnosis.

However, an employer should take all reasonable actions in support of their staff, such as regular appraisals, or if an Employment Agency is involved and knows about a diagnosis then it is assumed that the employer is informed by the agency. All employment application forms will include a question regarding disability as well.

Management will want to look at five areas to see if they are able to be of assistance:

- 1. What sort of adjustments could be used to help the employee stay useful to the organisation?**
- 2. What are the triggers and stressors that might affect their work?**
- 3. What are the signs that the employee is struggling?**
- 4. What are the Health and Safety issues?**
- 5. How will they know when the employee is incapable of further employment?**

The first, important, point to bring up with your employer is that there is a Government scheme available for you or your employer to assist in paying the costs of any changes. It is called 'Access To Work'. Read more about it here: www.gov.uk/access-to-work.

This scheme can be used, for example, to pay for you to get taxis to and from work so that you can either work different hours or avoid public transport. Employers can use it to pay for their own 'reasonable adjustments'.

"My initial fear after diagnosis was that I would have to stop working, but my employer has made it possible for me to continue working by making adjustments to my role."

Some of the practical adjustments that are 'reasonable' for employers can include reminders, changes to work times, or time off for appointments. These have all been covered in this resource by the examples shared. Another effective adjustment is when a 'buddy system' is put in place. This could be formal, but more effective when informal.

“What kept me going, see, the guys that I worked with, an absolutely fantastic group of guys, couldn’t ask for better honestly and I think that’s what really kept me going.”

State Benefits

When deciding about leaving work early due to any long-term illness or disability, one has to consider State Benefits. Without going into too much detail, there are two main benefits to consider.

Employment Support Allowance is payable, and can be claimed once your Statutory Sick Pay ends. If your organisation pays higher sick pay this will be taken into account. Get Well notes are required to be sent until you are told otherwise. Please check requirements at: www.gov.uk/employment-support-allowance.

Personal Independence Payment (PIP) is payable if you are either in or out of work, again under particular circumstances. Read more about it here: www.gov.uk/pip.

This latter benefit is being renamed Adult Disability Payment in Scotland when the devolved government takes over PIP in March 2022 (correct at time of writing this publication).

Also, under very specific circumstances, one can receive 25% discount for Council Tax, or a full 100% if you live alone. Find out more here: www.gov.uk/council-tax/discounts-for-disabled-people.

Having a diagnosis of dementia automatically allows access to a Blue Badge; you apply to your local authority for one, which will enable you to use Disabled Parking Bays. An employer does not have to provide Disabled Parking Bays under 'reasonable adjustments'; this has to be determined by a Tribunal, because it is not always practical.

Chapter 3

Alternatives to paid work

At the beginning, I said that I gave up paid work so I could do what I wanted. To me, this means campaigning and researching around dementia, whilst creating memories for my loved ones. To others, it can be anything that they find possible: volunteering, gardening, travelling etc.

Many of the people I have spoken to have said that they can now do the long-haul holidays which they have always wanted to do at their own pace, for example. Obviously, at the time of writing, COVID-19 has dashed the hopes of many. One person I spoke to wished dearly to return to Glastonbury. However, he has the same diagnosis as myself (Posterior Cortical Atrophy; PCA), and from my own experience as someone who loved loud and lively rock concerts, over time his senses will become easily overwhelmed by such shows. Indeed, I had to cancel some shows I wished dearly to attend. This is also reflected in the fact that I have to play my music softer than before; one has to learn to adapt according to the progress of one's symptoms.

This adjustment is also required in your approach to work (both paid and unpaid).

As seen above, your employer has to take this into account and there will come a time when both parties have to agree that you are medically unfit to carry on.

To use myself as an example, again, I have had to accept that I cannot travel far anymore (due to sensory overload), so my campaigning days are over. So I am now concentrating on administration and research.

PCA does not affect one's cognitive functions until the latter stages, so I am adapting my coping strategies to my disease. This is the best way forward.

There is now a burgeoning “Craftivism” movement within the dementia community in which people are learning new skills, or using skills they already have, to make objects, be they painting, photos, pottery etc. These activities are ideal for those with an artistic bent.

Read more here: www.dementiacreatives.org.uk/dementia-craftivists/what-is-craftivism.

There are many other ways of reacting positively to being unable to carry on with paid employment. For inspiration please look at the Life Changes Trust website: www.lifechangestrust.org.uk/our-dementia-programme. This website gives many examples of what is possible. This organisation works solely in Scotland.

Other examples can be found on the DEEP website: www.dementivoices.org.uk.

Final Thoughts

I hope that this resource encourages people to look beyond the boundaries, and perceived shame, of receiving a dementia diagnosis.

Most importantly, my wish is that people can find fulfilment in a life with dementia, and be able to find some sort of activity that they can enjoy: many studies have shown that using the brain is helpful for one's general physical health, and this does not stop being the case if one has dementia.

Lastly, many thanks to Paula Brown as mentor, and my own brother John Robertson for his academic guidance without whose input I would not have been able to manage this project.

A great quote to end on is:

“Focus on what you can do and keep striving”

Resources used in my research

- ▶ 'Somebody I used to know'; Wendy Mitchell, Bloomsbury, 2018
<https://www.bloomsbury.com/uk/somebody-i-used-to-know-9781408893340/>
- ▶ 'Slow Puncture'; Peter Berry with Deb Bunt, Book Guild, 2020
- ▶ RITCHIE, L., TOLSON, D., & DANSON, M. (2018). Dementia in the workplace case study research: Understanding the experiences of individuals, colleagues and managers. *Ageing and Society*, 38(10), 2146-2175
<https://www.cambridge.org/core/journals/ageing-and-society/article/dementia-in-the-workplace-case-study-research-understanding-the-experiences-of-individuals-colleagues-and-managers/C9EB981FD7B232F0696B9A8410871972>
- ▶ Living with Dementia – Employment; Alzheimer’s Society, 2020
<https://www.alzheimers.org.uk/get-support/publications-and-factsheets/living-dementia-employment>

About the author

I started work polishing Smarties, later becoming a Benefits Administrator before caring for the elderly. I was initially diagnosed with Frontal Temporal Dementia in 2016, aged 58, however after many tests and different symptoms I was finally diagnosed with Posterior Cortical Atrophy which is the same dementia as Terry Pratchett had. I was glad to give up work but soon realised that many people's experiences were very different, so I wrote this resource to give others the information required to enable them to make informed choices.



Getting in touch

If you have any queries or wish to share your views and ideas, you can contact the Life Changes Trust in a number of ways:

Phone: 0141 212 9600

Email: enquiries@lifechangestrust.org.uk

Website: www.lifechangestrust.org.uk