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Information on

Cancer-related Cognitive Changes (CRCC)?



To watch the cancer-related cognitive changes (CRCC) videos, please refer to the NHS Greater Glasgow and Clyde YouTube Channel.

What are Cancer-related Cognitive Changes (CRCC)?

After cancer treatment some people notice changes in their concentration and the way they think. Women with breast cancer were the first to report these problems which they linked to their chemotherapy treatment. They called these changes 'chemobrain' or 'chemofog' but it is not clear what causes these changes, so calling them 'chemobrain' may not be accurate. Following radiotherapy treatment, throughout and after hormonal treatment, people can also experience these attention and memory changes. Cancer-related cognitive changes (CRCC) and mild cognitive impairment are other terms used, but cognitive simply means thinking. Most people who have cognitive changes are able to do everyday things but they may notice they aren't as able to do some things quite as well as they did before they had cancer. The changes are often mild and subtle. They aren't progressive and do improve over time. But if you do have them, they can affect your everyday life and this can be quite frightening for some people.

What causes CRCC?

It is not known for certain why these symptoms happen and why they happen in some people but not in others. Doctors and other researchers believe that several factors are likely involved in causing the symptoms of cancer-related cognitive changes, including:

- the cancer itself
- cancer treatments, such as chemotherapy, radiotherapy and antibody treatments (especially if you have more intensive treatments such as high-dose chemotherapy and a stem cell transplant)
- side effects of cancer treatments,
- hormone changes caused by cancer treatments, such as an early menopause.

Researchers recently used fMRI scans to look into whether the brain works differently for people who have had cancer treatments. One study carried out by Professor Ferguson and colleagues

involved identical twins; one who was treated for breast cancer which included surgery and chemotherapy and the other who did not have breast cancer. The sisters completed a series of memory tests whilst their brains were being scanned.

The tests involved paying attention, remembering information and having a good reaction time. Although their actual performance was the same, the twin with chemotherapy had a lot more activity in her brain. This extra brain activity suggests that the brain has to work a lot harder to complete these tasks which previously they would have carried out with ease.

The Cancer Research UK website (www.cancerresearchuk.org) has useful information about cancer-related cognitive changes and current research into the condition.

How might I be affected?

Knowing more about these memory and concentration changes can be helpful in managing them. The changes can come and go but how much you notice them seems to depend on what you are doing. These changes can be frustrating and can affect how you feel. Experiencing CRCC can impact on your home and work life.



"It got to the stage where I stopped meeting up with friends because I couldn't keep up with the conversation. I couldn't remember and the subject had changed, I still was on the previous subject. Somebody would say something and my mind went a total blank, I had no idea what they were talking about and yet I had been involved, what I thought was involved, in the conversation."

(Jess, Breast Cancer Patient)

The type of difficulties you may notice are:

- Your memory – forgetting dates, phone numbers or names that you would normally remember
- Concentrating on tasks or on your work – even on simple things like preparing a meal
- Thought processes that you normally find easy – such as making shopping lists, doing puzzles or adding up numbers in your head
- Multi-tasking – doing more than one task at a time
- Finding the right words for things
- Following the thread of a conversation
- Making plans
- Learning new facts – you might get confused easily or take longer to learn things.

Coping with CRCC

Individuals' stories highlight that these memory changes are often invisible to other people. One of the main challenges after finishing treatment is that everyone expects you to be back to normal, but it might not be that easy. People around you are willing you on but you might not be ready as adjusting emotionally takes time. There are many practical tips which can help in managing these memory and concentration changes.

There are general coping strategies which can improve our general wellbeing and in turn can help our thinking and concentration.

"I was using reminders...and for me, everything pointed to slowing down and regaining my confidence. " (Dougie, Prostate Cancer Patient)

Manage fatigue or tiredness:

✓ **Take breaks**

- Fatigue can make attention more difficult.
- Work for short periods of time, planning breaks into your day.

✓ **Work at your best time of day**

- Are you a morning/afternoon/evening person?
- Complete your most difficult tasks when you have the most energy.

✓ **Start a bedtime routine**

- If sleep is a problem, start to develop a routine before bed, preparing your body for sleep, and making it more likely you'll get a good night's sleep.

✓ **Limit caffeine**

- If you're particularly sensitive to caffeine, avoid it any time after noon.
- This will help you get a better night's sleep if caffeine is a factor.



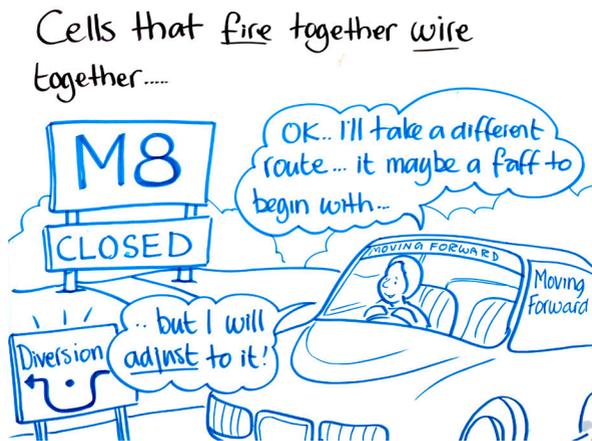
Look after yourself:

- ✓ Don't stress(!)
 - Easier said than done! We know problems with attention and memory can cause stress, but stress can make this worse!
 - What works for you? (*exercise, talking to friends, mindfulness, a bath etc.*)
 - For ideas on what could help you, visit: www.stepsforstress.org
- ✓ Let others help
 - Often others will want to help. If they do, explain what you find difficult and how you'd like them to help.
- ✓ Notice how you feel
 - Attention and memory problems can cause anxiety and low mood, and often our emotions can sometimes get on top of us. Unfortunately these emotions can make attention and memory worse, and become a vicious cycle. Like with stress, do what works for you to process your emotions, but if you notice that you can no longer manage your emotions, it may help to speak to your GP about what can help.



Cognitive Coping Strategies

The other type of coping strategies involves doing things in a different way to help “compensate” or work around the changes to attention and memory. This can be referred to as cognitive rehabilitation. For example, this might involve using a diary, or using visual images to remember. You could think of using cognitive coping strategies as being similar to using a road diversion. Over time, this new route will become easier and still gets you to your destination!



The following cognitive coping strategies have been divided into attention; memory; executive function (planning and organisational skills) and are based on this cognitive rehabilitation approach which serves to put into place various ways of working around the memory and concentration changes.

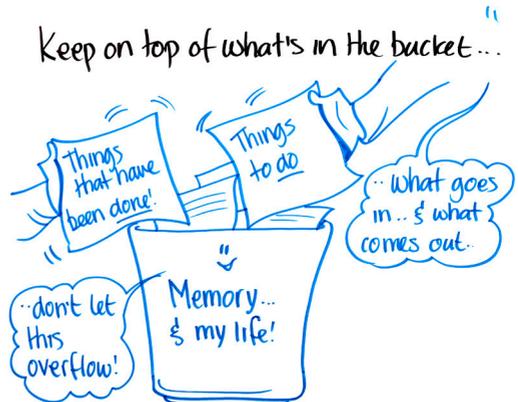
"I used to have one pad and pen and if I remembered something, I'd put it down, mark it down. But I'd be up the stairs and by the time I got down the stairs trying to remember something, I'd have forgotten it. So, what I did was put a pad and pen in every room and that meant I had five notepads; I'd collate them all at the end of the week and I had my shopping list."

(Jess, Breast Cancer Patient)

Attention:

Attention is the basis for learning and memory; you must first pay attention to something before you can put it to memory. It is a limited resource. We can think of it as a bucket that can only hold so much. When it's full it can overflow, meaning we can't pay attention to things or remember them in the future.

It can be filled up by many different things such as; noisy environment, fatigue, physical ill-health, medication, and stress/anxiety, making it hard to pay attention.



How to improve your attention:

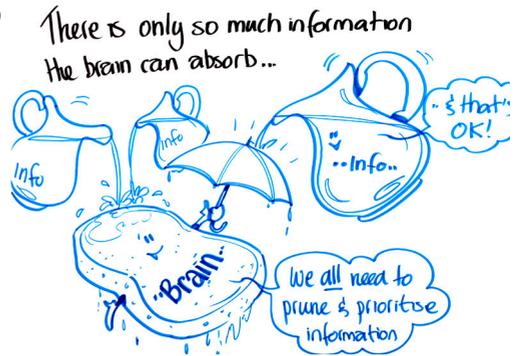
Set up the right conditions:

- ✓ Try to remove distractions
 - (e.g. by turning of the tv/radio if someone is talking to you)
 - A quiet, calm atmosphere will help.
- ✓ Focus on one thing at a time.
 - Don't try to take in too much information at once.
- ✓ Make a plan
 - Apply structure or break tasks down into smaller pieces. This makes it easier to get back on track if you get distracted.
- ✓ Keep a notepad handy
 - (e.g. by the telephone, in your bag or pocket)

Jot things down. The more you use it, the less you're likely to need it.

Memory:

Memory relies on many stages to work effectively, attention being one of them. We can think of it as a filing cabinet. Memories must be filed correctly in order to find at a later date. Similar to our attention capacity, there are many factors which can affect this process of filing and finding memories.



How to improve your memory:

Changes to your home:

- ✓ A place for everything, and everything in its place
 - This can help for keys, wallet etc. It'll mean that a habit is soon formed and you don't rely on memory. It can also help others to help you.
- ✓ Remind yourself
 - Using a whiteboard/chalkboard/corkboard in your home can do this for you,
 - Try adding appointments for the week, shopping lists or things to do.
 - Get in the habit of glancing at it every time you enter and leave the room.
- ✓ It's okay to rely on tools
 - Diaries, calendars or notebooks (either paper or electronic) can help keep all important information in one place.
 - Like with the chalkboard, try to check these regularly. Mobile phones have plenty of apps that are designed for reminding you of tasks or lists. See what works for you.
- ✓ Keep a notepad handy
 - (e.g. by the telephone, in your bag or pocket)
 - Jot things down. The more you use it, the less you're likely to need it.

When learning new information:

- ✓ Make it as easy as possible
 - Try to get rid of distractions such as tv or radio.
 - Take your time and write it down.
 - Repetition helps learning, repeat the information as much as possible.
- ✓ Tricks and strategies
 - Rhymes, rules or stories can help our memory.
 - Making associations with something meaningful or forming visual images helps

Executive function (planning and organisational skills):

Executive function is one of the most complex aspects of our thinking. We can think of it as the chief executive or even the conductor of our brain. He plans, organises, adapts, directs, weighs up decisions and decides what the priorities are. The factors which affect our attention and memory also can impact on our executive function.

'Don't leave the house by installments...



How to improve your executive function:

Staying organised:

- ✓ A step-by-step approach
 - Relying on visual organisational aids can help our thinking and planning
- ✓ It's okay to rely on tools
 - Organisers, computers or phones with alarms can help keep you on track,
- ✓ Ask for written directions with spoken instructions where possible
 - Like with the chalkboard, try to check these regularly. Mobile phones have plenty of apps that are designed for reminding you of tasks or lists. See what works for you.
- ✓ Keep a notepad handy
 - *(e.g. by the telephone, in your bag or pocket)*
 - Jot things down makes it easier to stay organised.

Managing your time and space:

- ✓ Lists, lists, lists
 - Make checklists and to-do lists and estimate how long tasks will take.
 - This will help you prepare and prioritise, and make planning easier.
- ✓ Breaking tasks down
 - Large activities can be broken into parts to make them more achievable.
- ✓ Tidy space, tidy mind
 - Minimising clutter and working in an organising space will really help you think.
 - Scheduling a weekly time to clean and organise will help keep on top of this
- ✓ Reduce distractions
 - Try to get rid of noises around you such as tv or radio.

Getting help and support

The adjustment to the emotional and mental side of things after treatment is also invisible to others. They may not understand that you're feeling more emotional or see the struggles with your concentration. The more people that know more about these memory and concentration changes, the more they will understand and the easier it will be for you to adjust and to do this in your own time.



Support returning to employment



If you are returning to work, talk to your employer and occupational health department about how you are feeling so that they are aware of any potential difficulties you might have when you are back.

Ensuring that employers provide sufficient

accommodations for people with “invisible conditions” is a government priority. There are several agencies which provide information and advice on workplace health and wellbeing. Please see below for contact details of these agencies.

Invisible conditions include physical or mental difficulties which have a substantial and long-term adverse effect on an individual's ability to carry out day to day activities. The employment specific support agencies can guide you through what you are entitled to in order for you to carry out your job.

These support services also includes advocating on your behalf so that employers can meet their obligations under the Equality Act.

The Equality Act requires employers to take into consideration the impact of a condition on the employee's ability to carry out their role and to adjust the role to accommodate for this. The legal term for this is 'reasonable adjustments'.

In the case of cognitive changes examples of adjustments that may be considered to be reasonable are as follows:-

- Giving you longer to complete tasks
- Temporarily giving some of your work to a colleague
- Giving you extra breaks if you feel tired
- Flexible working arrangements
- Allocating a buddy or mentor to provide support
- Allowing you to have a phased return to work following a period of absence
- Giving time off to attend support groups, counselling or for psychological treatment such as cognitive behaviour therapy (CBT)
- Monitoring how you are coping with work including workload
- Providing written instead of verbal instructions



Employment-specific support agencies:

There are several national agencies which provide free, impartial and professional work-related advice and support for people with long term conditions.

Scottish Centre for Healthy Working Lives

Advice line: 0800 019 2211

The Advice line offers immediate, free and confidential help and information on any matter concerning health and wellbeing in the workplace, including health and safety, occupational health and health promotion.

Website: www.healthyworkinglives.com

Fit for Work Scotland

Advice Line: 0800 019 2211

Fit for Work Scotland is a free advice and assessment service supporting employees, employers and GPs to manage a return to work.

Website: fitforworkscotland.scot

Access to Work

If the help you need at work is not covered by your employer making reasonable adjustments, you may be able to get help from Access to Work.

You need to have a paid job, or be about to start or return to one. You'll be offered support based on your needs, which may include a grant to help cover the costs of practical support in the workplace.

An Access to Work grant can pay for:

- special equipment, adaptations or support worker services to help you do things like answer the phone or go to meetings;
- help getting to and from work

You might not get a grant if you already get certain benefits. The money does not have to be paid back and will not affect your other benefits.

Check: <https://www.gov.uk/access-to-work> for further information

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