

COGNITION:

HOW STEM CELL TRANSPLANT CAN AFFECT YOUR **MEMORY AND CONCENTRATION**



**ANTHONY
NOLAN**

saving the lives
of people with
blood cancer



At Anthony Nolan we take great care in providing up-to-date and accurate facts about stem cell transplants. We hope the information here will help you to look after yourself.

Each transplant centre will do things differently, so this booklet is just a general guide and isn't intended to replace advice from your doctor and transplant team.

Please speak to your transplant team for more details about your own situation, as they will be able to give you personalised, specific advice.

Ordering more copies

If you'd like to order more copies of this guide please get in touch with us on patientinfo@anthohnolan.org

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patientinfo@anthohnolan.org

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ANTHONY NOLAN
PATIENT SERVICES

WHAT'S IN THIS BOOKLET?

Change in cognition (memory and concentration) is a common side effect of a stem cell transplant, but it is not widely discussed or understood. This booklet explains what cognition is and the changes that can occur following a transplant, along with the causes and symptoms you might experience.

We'll also give you coping strategies and tips for how to manage these symptoms as part of your recovery, along with help for returning to work and education.

Finally, it explores how changes in cognition can impact your wellbeing and how this can be applied to your everyday life.

Don't feel that you have to read this booklet all at once. You might only want to take in small sections at a time.

This guide has been written with the first-hand advice of our remarkable patients and the expert guidance of healthcare professionals. They have shared their experience to help you through your recovery.

If you have any questions or would like further advice, you can call our helpline on **0303 303 0303** or email us: **patientinfo@anthonyolan.org**

Acknowledgment: The content of this booklet has been based upon Cancer Related Cognitive Changes produced by Macmillan and NHS Scotland. The information was developed following a Transforming Care after Treatment (TCAT) Cognitive Rehabilitation project. All permissions have been given. Thanks to original author Dr Natalie Rooney, Macmillan Principal Clinical Psychologist, NHS Greater Glasgow & Clyde, Macmillan Cancer Support and NHS Education Scotland. A series of videos based upon the original booklet is available at:

www.nhsggc.org.uk/cancerandmemory

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KEY FACTS

WHAT IS COGNITION?

Cognition simply means 'thinking'. It can be how we carry out everyday tasks, how we remember names and dates, how we plan our day and how we retain and process information.

IS IT NORMAL FOR COGNITION TO BE AFFECTED AFTER A STEM CELL TRANSPLANT?

High dose chemotherapy, as well as some of the medicines used after transplant, can cause changes in cognition. This is a common side effect of a stem cell transplant but it doesn't happen to everybody. Unfortunately, there is no way of predicting who will be affected.

These changes in cognition are not that well understood so they are not always discussed before transplant. Similar effects can also be seen after treatment for other types of cancer.

WILL TREATMENT IMPROVE MY COGNITION AFTER A STEM CELL TRANSPLANT?

There aren't any treatments for this at the moment, but methods of cognitive rehabilitation can help 'retrain' your brain to be able to carry out tasks. This booklet highlights these methods as well as cognitive coping strategies that can help manage symptoms of Cancer-related Cognitive Changes (CRCCs).

WILL I ALWAYS FEEL LIKE THIS?

Changes in cognition can occur at different times following a stem cell transplant. Generally, your previous level of cognition will return, although this can take some time.

In some cases, you might never feel like you return to your 'normal' level of thinking. In these situations, practical adjustments to your lifestyle can help you manage the symptoms. It's also important to remember that our normal ageing process can cause changes in cognition.

WHAT ARE CANCER-RELATED COGNITIVE CHANGES (CRCCs)?

'Cancer-related Cognitive Changes' (CRCCs) is a term used to describe changes in a person's ability to concentrate and think following cancer treatment. These changes are sometimes also referred to as 'chemobrain' or 'chemofog'.

Most people who have cognitive changes are able to do everyday things, but they may notice they aren't able to do some things quite as well as they did before they had cancer. Changes can often be mild and subtle.

Thankfully, CRCCs aren't progressive and they do improve over time. However, they can affect your everyday life so this can understandably be quite frightening for some people.

WHAT CAUSE CRCCs?

It is not yet fully understood why these symptoms occur and why they affect some people but not others. Research into the brain activity of people who had cancer treatment found that their brains functioned in the same way as those who had not had cancer treatment, but the brains of the cancer patients had to work much harder to complete the same tasks.

Factors likely to be involved in causing CRCCs include:

- Cancer treatments such as chemotherapy, radiotherapy and antibody treatments.
- High-dose chemotherapy and a stem cell transplant.
- Side effects of cancer treatments.
- Hormone changes caused by cancer treatments, such as an early menopause.

It is thought that 30-40% of stem cell transplant patients will experience cognitive changes after an allograft (receiving stem cells from a sibling or unrelated donor). Patients who have a full intensity transplant (i.e. higher doses of chemotherapy and radiotherapy) are thought to be at higher risk of cognitive changes. The rate is much lower after an autograft (when you receive your own stem cells).

New treatments such as Chimeric Antigen Receptor T-cell (CAR T-cell) therapy can affect cognition in the short term although its long-term effect on cognition is not yet clear.

Further research needs to be carried out to determine what other factors could affect who will experience cognitive changes after transplant and who will not.



WHAT ARE THE EFFECTS OF CRCCs?

Knowing more about how our brain ‘thinks’ helps us to understand how these changes can affect our memory and concentration. We’ll look at attention, memory and our planning and organisational skills.

Attention

Attention is the basis for learning and memory. You must first pay attention to something before you can put it into your memory.

Attention is a limited resource. 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 afterwards.

Our attention can be filled up by many different things such as:

- a noisy environment
- fatigue (extreme tiredness that does not get better with rest or sleep)
- physical ill-health
- medication
- stress or anxiety.

These factors can make it difficult to pay attention to things we need to.

Memory

Our memory follows many different stages in order to work effectively (attention being one of these stages). We can think of it as a filing cabinet: memories must be filed correctly in order to find them at a later date.

Many factors affect this process of filing and finding memories.



Executive function (planning and organisational skills)

Executive function is one of the most complex aspects of our thinking. It's like the chief executive or the conductor of our brain. It 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.

Experiencing CRCCs can be frustrating. It can have an impact on how you feel, your work and your home life.

It's important to remember that these changes can come and go. How much you notice them may seem to depend on what you are doing at that time.

You may struggle with things such as:

- remembering dates, phone numbers or names
- concentrating on simple tasks or on your work
- making shopping lists, doing puzzles or adding up numbers in your head
- multi-tasking
- finding the right words for things
- following the thread of a conversation
- making plans
- learning new facts.



There is still a lot to learn about CRCCs and it is difficult to predict whether or how you will be affected by it. So, knowing what to look out for is important.

Report any changes you experience in your concentration or your memory to your medical team. This will enable them to give you advice and support, as well as monitor your symptoms over time.

'Chemo brain or chemo fog is a strange condition and it can be incredibly frustrating. I regularly struggle to find the right word to explain something, or to remember people's names.'

Steve, stem cell transplant recipient

COGNITIVE COPING STRATEGIES

Unfortunately, there is no immediate fix for CRCCs. However, coping strategies can be followed which involve doing things in a different way to help compensate for, or work around, any changes in your attention or memory.

This is often referred to as cognitive rehabilitation. Think of this as being similar to following a diversion on a road: it still gets you to your destination and over time this new route will become easier to follow.

The following suggestions are based upon the cognitive rehabilitation approach, to help improve your attention, memory or executive function (planning and organisational skills). They are a general guide to help you find out what works best for you.

Don't attempt all the strategies at once - try them one-by-one and see what works for you.

Attention:

- Set up the right conditions by removing distractions.
- Focus on one thing at a time.
- Don't try to take in too much information at once.
- Apply structure or break tasks down into smaller pieces.
- Write things down.

Memory:

- Always keep important items in the same place, such as keys, your wallet, purse etc. This will help your brain to form new habits rather than rely upon your memory.
- Use tools such as a whiteboard, chalkboard or cork board to remind yourself of important things. Add appointments, shopping lists or things to do. Get in the habit of glancing at it every time you enter and leave the room.
- Use a diary or notebook (either paper or electronic) to keep all important information in one place.
- Repetition helps learning, so repeat the information as much as possible. Rhymes, rules or stories can help our memory.
- Making associations with something meaningful or forming visual images helps, such as associating someone's name with a visual feature like glasses or a beard.

Executive function (planning and organisational skills):

- Use a step-by-step approach with calendars, organisers (paper and electronic) and apps to help with planning.
- Use computers or phones with alarms to help keep you on track.
- Ask for written directions with spoken instructions where possible.
- Keep a notepad handy e.g. in your bag, by the phone or in your pocket.

It can take time to see an improvement in symptoms with CRCCs. Like other aspects of transplant recovery, this may mean that you have to adapt parts of your life.

Although this can be frustrating, using these strategies on a regular basis can help you to manage your CRCCs and improve your quality of life.

Specialist occupational therapists (OT) and psychologists can assess how cognitive changes affect your daily life, and help you plan how to manage symptoms. Not all transplant centres have these specialist OTs or psychologists, so discuss this with your medical team. If it's an option, a referral can be made.

'Working on a computer or reading a book just wasn't possible for about three months. After that I would say that things improved very gradually, although I still have problems with short-term memory.'

Mel, stem cell transplant recipient



WELLBEING AND ITS INFLUENCE ON CRCCs

Improving our general wellbeing can help our thinking and concentration. Here are some areas to focus on:

Emotions

Side effects of treatment and the long period of recovery mean that the psychological impact of a stem cell transplant can be significant for many patients. Low mood and depression are not uncommon, and they can make attention and concentration worse.

Experiencing CRCCs can also feel isolating and distressing. Problems with memory and concentration are difficult to explain. It's not a visible side effect so it's not always obvious that you are struggling.

Expectations (from others and those you place on yourself) can cause anxiety and a sense of not being able to cope with everyday tasks. This can affect your mood and confidence which can have an impact on your relationships, socialising and quality of life.

It's important that you find ways to help calm some of your concerns through the strategies mentioned earlier, and also by talking to your family and friends. This will help them understand and support you.

Talking to your transplant team or GP is also essential as they will be able to discuss the different methods of support available. You can also read more advice in our booklet *Your Mental Health and Stem Cell Transplant*.

'Those around me at home, my friends and work colleagues have all adjusted to this change in me, and often step in to remind me of the word or name I'm searching for. It takes some getting used to but I've now accepted this is how I am after my treatment. I've learned to cope with it and not get stressed by it.'

Steve, stem cell transplant recipient

Fatigue

Fatigue is very common after a stem cell transplant and is one of the side effects that lasts the longest. Fatigue is not just physical but can be mental too, making concentration more difficult. So, managing your fatigue will also help you manage your concentration.

- Fatigue management is about planning your day and prioritising what needs to be done and what can wait.
- Do things at the times of day when you have the most energy.
- Have regular breaks.
- Accept that you will have days when you can do more and days when you need to give yourself a rest.
- There is further advice in our *Managing Fatigue After a Stem Cell Transplant* booklet.


Sleep

Lack of sleep will affect your concentration and memory. If this becomes a problem for you:

- Start to develop a routine before bed to prepare your body for sleep, making it more likely that you'll get a good night's sleep.
- Try not to nap too much during the day as this can quickly form bad sleeping habits - have an early night instead.
- Limit caffeine from the afternoon onwards.
- Reduce your alcohol intake.
- Begin to unwind an hour or so before you are due to go to bed by switching off screens and mobile phones.
- Try mindfulness or relaxation techniques.

Diet and exercise

It's very common to have a reduced appetite after a stem cell transplant and this can take a long time to return to normal. Poor nutrition and dehydration can affect your attention and memory, so improving your diet can also have a positive effect on your cognition.



'Exercise, quality sleep and staying off alcohol really does help. Increased stress definitely affects all aspects of this condition.'

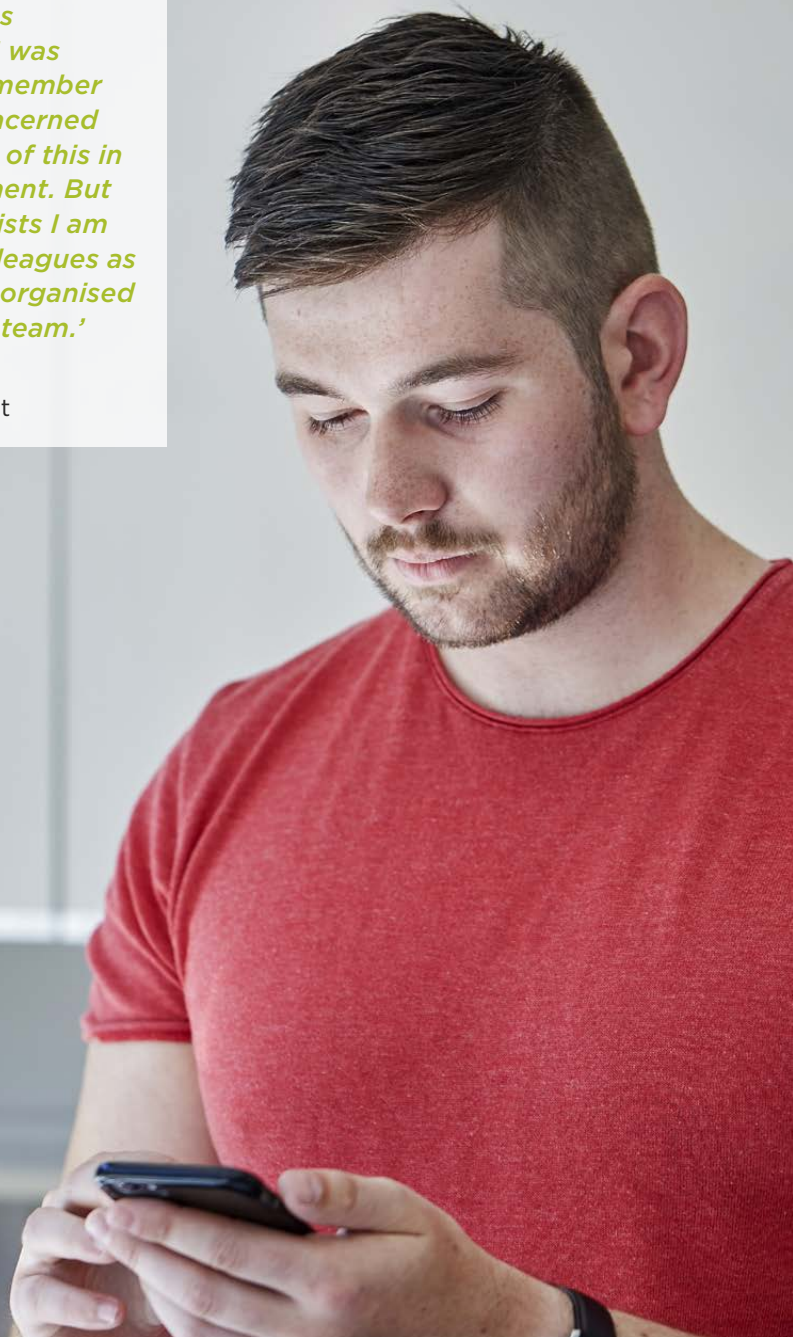
Mel, stem cell transplant recipient

- Don't put pressure on yourself to eat large meals – try a 'grazing' approach to food, eating little and often.
- Choose foods that have higher calories so you get more energy without having to eat lots. Try full fat milk, cream stirred into soup or cheese on a baked potato.
- If you need an energy boost, try high-protein foods like eggs and cheese. Snacks such as dried fruit and nuts have lots of energy too. Exercise can help with fatigue, sleep, low mood and anxiety, so it can also have a positive effect on your memory and concentration.
- Find exercise that you enjoy and only do what you feel you can manage.
- Ensure it's safe by checking with your transplant team, especially during your early recovery from transplant.
- Remember: any type of exercise is good - this can be a five minute walk around the garden or a longer walk around the park, a jog or yoga. It can also include activities such as housework or gardening.

Find more about exercise and stem cell transplant in our *Essential Guide to Diet and Physical Activity* booklet.

'Following treatment, I found that I was concerned that I was struggling to remember things. I was concerned about the effect of this in a work environment. But by good use of lists I am now seen by colleagues as one of the most organised members of the team.'

Robert, stem cell transplant recipient



RETURNING TO EMPLOYMENT OR EDUCATION

If you are thinking of returning to work or education, talk to your employer or tutor as early as possible so you can keep them up to date with how you're feeling.

Returning to work and education after a stem cell transplant might be a relief, or a bit scary, or both. Although most employers are supportive in doing what they can to enable your return, the support can vary. Returning to education after a stem cell transplant is a good step in your recovery, but it can also be daunting. Feeling like you have to 'catch up' can be overwhelming.

It's important that you take your time and get the right support. Talk through any concerns you have about your memory or concentration with line managers or tutors. This will enable you both to decide on the best way forward. Even with the best intentions, sometimes it's difficult for others to understand the side effects of a stem cell transplant and the length of recovery.

If your tutor, employer or financial benefits application requires more information, ask a member of your transplant team - such as your clinical nurse specialist (CNS) - to write you a supporting letter. You could also give them this booklet or our guide *Work & Stem Cell Transplant: Information for Employers*.



ANTHONY NOLAN CONTACT DETAILS

ANTHONY PATIENT SERVICES

If you or a loved one is affected by a stem cell transplant, there are many ways we can support you:

NEED TO TALK?

The Patient Services team at Anthony Nolan is here for you. Call us on **0303 303 0303** or email: **patientinfo@anthonymolan.org**

GET CONNECTED

Find support from other patients and their families by joining our **Patient and Families Forum** at: **anthonymolan.org/forum**

FIND INFORMATION

Our website has lots of helpful information about what it's like to go through a transplant. Download or order our booklets for free, and find links to other places where you can get support at: **anthonymolan.org/patients-and-families**

OTHER USEFUL CONTACTS

ACCESS TO WORK

gov.uk/access-to-work

Support at work from the UK government for people with a health condition or disability, including Access to Work grants.

BRITISH ASSOCIATION FOR COUNSELLING AND PSYCHOTHERAPY

bacp.co.uk

01455 88 33 00

Information about counselling and therapists in your area.

CANCER RESEARCH UK

cancerresearchuk.org

0300 123 1022

Extensive information on cancer including cancer-related cognitive changes and current research into the condition.

GOV.UK

gov.uk

Information about UK government services including benefits, employment and money matters.

MACMILLAN CANCER SUPPORT

macmillan.org.uk

0808 808 00 00

Practical, financial and emotional support for people with cancer, their family and friends.

MAGGIE'S CENTRES

maggies.org

0300 123 1801

A network of drop-in centres for cancer information and support. Includes an online support group.

NHS

nhs.uk

111

Information about treatments, conditions and lifestyle. Support for carers and a directory of health services in England.

NOTES

A series of 15 horizontal dotted lines spaced evenly down the page, providing a guide for writing notes.

'CHEMO BRAIN OR
CHEMO FOG IS A STRANGE
CONDITION AND IT CAN BE
INCREDIBLY FRUSTRATING.
I REGULARLY STRUGGLE TO
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Steve, stem cell transplant recipient



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