



Primary to early secondary school

Learning curve: education and socialisation after childhood cancer

For children, parents and teachers

Learning curve: education and socialisation after childhood cancer An information booklet for children, parents and teachers Primary to early secondary school First published 2015 Paediatric Integrated Cancer Service

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Introduction

Cancer brings many challenges to children and their families. The disruption caused to normal life processes can result in short- and long-term changes that may alter thinking, behaviour and emotional skills. Some of these changes may be of benefit, such as a more mature or positive approach to relationships, while other changes may present challenges, like struggling to follow instructions or taking longer to complete

'Cognitive late effects' is the term used to describe the difficulties in thinking skills that can occur following treatment for cancer. While these difficulties are usually mild and only affect a small number of children, they can have an impact on academic achievement and social participation. Some children will therefore require additional support and assistance from parents, teachers or health professionals to meet their full potential.

This booklet is designed to be a general reference guide to help you identify, address the thinking, learning and behavioural or emotional difficulties that children may experience following treatment for cancer. Everyone is unique and the issues discussed in this booklet may not apply to your child. If you are concerned about your child's thinking skills, behaviour or emotional wellbeing, please discuss this with your doctor in order to access appropriate support.

Learning is a complicated business

Children are busy learners. They love to explore new things and may ask you lots of questions along the way. The way children learn is affected by the experiences they have with their world and the stage they are at in terms of brain development. Cancer and cancer treatments can interrupt both of these processes. The types of difficulty with thinking skills and behaviour that may arise following treatment will depend on the learning stage a child has reached prior to their cancer diagnosis and the length and intensity of their illness and treatment.

Children diagnosed at a very young age have had limited time to explore and interact with their environment. They are often physically restricted during periods of illness and spend much of their time around adults rather than other children their age. They may also be less willing to engage in unfamiliar activities or with new people due to the experiences they have had in hospital or the restrictions placed on them during treatment.

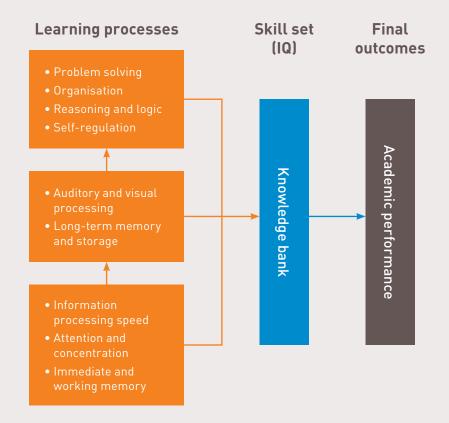
It is important to remember that a number of other factors can also affect how a child learns and may result in fluctuations in how they perform day to day. These may include:

- tiredness (physical or mental fatigue)
- sensory difficulties (such as hearing or vision loss and motor impairment)
- emotional difficulties (such as low confidence, sadness or high levels of worry and stress).

Impairments in physical, sensory or emotional areas can often look the same as the thinking difficulties described here. Children who have been treated for cancer are at increased risk of problems in these areas as a result of their treatment. It is therefore important to have these areas assessed if you believe they may be contributing to your child's problems with learning or social participation.

The diagram below shows some of the key thinking skills required to process and learn new information. Basic thinking skills like being able to take in information quickly, concentrate and hold information in memory develop at an early age. These more basic thinking skills are important for the development of more complex abilities like planning, organisation and problem solving which mature during adolescence and early adulthood.

A child may experience difficulties in one or multiple thinking skills and this will affect how well they perform when compared with their peers. As a general rule, children do not lose skills they have already acquired before becoming sick but may have difficulty developing new skills. For example, a child who becomes ill at age 10 and has already mastered early literacy skills will not lose this ability but may experience difficulty with new or developing skills, such as reading more complex material or organising ideas to write a story.



Every child has their own learning style

All children and adolescents, regardless of their medical history, have strengths and weaknesses in their thinking skills. For example, some children are naturally good at academic-based tasks while other children need to put in extra effort to keep up with their peers. Some children like to talk and are good at language or word-based tasks, but other children are better at putting together puzzles and understanding pictures.

Useful questions to ask yourself when considering whether your child may have difficulty with thinking skills are:

- Does my child have trouble following instructions or remembering information on a daily basis?
- Is my child often falling behind in class and can't seem to keep up?
- Is my child more forgetful or disorganised than their friends?
- Does my child show very different behaviours from other children their age?

Understanding your child's learning style can help you choose the right strategies to maximise how well they do at school and with their friends. It is important to remember that if a child thinks they can't do something they usually won't do it. No-one wants to fail at a task, especially in front of a classroom audience! Building success into any program is therefore crucial. All of us like to do well and receive praise. So it is important to design work tasks that draw on your child's strengths and use their own performance as a benchmark to improve on rather than comparing them with their friends and classmates. Setting goals at a realistic level will help your child experience success which will motivate them to continue using strategies and apply effort in their work.

What do 'cognitive late effects' look like?

Children are affected in different ways by cancer and its treatments. While children can experience changes in a variety of areas, certain types of thinking and behavioural difficulties are more common following cancer treatment.

They include difficulty with:

- information processing speed
- attention and concentration
- memory
- executive functions (such as planning, organisation and monitoring of behaviours).

As shown in the diagram on page 9, these skills are learning processes. So some children and adolescents who have had cancer will need to put in more effort and time to learn new skills. In general, these difficulties are not restricted to learning a particular type of material, for example, learning letters or sounds. They will instead become evident in whatever skill a child is developing at the time. So a young child who is at the stage of learning to read may initially not be as fast or accurate a reader as the other children in their class and will need to do more work to get to the same level of proficiency as their peers.

It is important to note that while some children and adolescents who have been treated for cancer may require extra support and alternative strategies to learn a new skill, most will be able to maintain an appropriate skill set for their age. That is, their intellectual level (IQ) and general functioning will usually be age-appropriate. There will be a very small number of children at risk of reduced intellectual function and significant academic difficulties. These are children who received very intensive treatment. particularly brain radiation, at a young age, suffered significant neurological complications or had a pre-existing developmental or intellectual disorder.

While cognitive late effects may develop at any stage during the child's illness or treatment, they are more often seen in the months to years after treatment is completed. It is important to note that most children who have had cancer will not experience difficulties. The remaining sections of this booklet will provide information and strategies for helping children who do demonstrate difficulties with thinking and learning following treatment.

Information processing skills

Information processing refers to the ability to take in and manage the information collected by our senses. When we talk about information processing we usually refer to the speed at which a person can process information. Information processing speed is important for all forms of thought as it affects the amount and quality of the information a person can manage at any one time. As children get older their information processing speed gets guicker. Part of this increased efficiency is due to improvements in attention skills which allow a person to focus more effectively on what is important while filtering out other less important information.

Information processing difficulties can present in many ways. The most common indicators include:

- difficulty completing classwork or homework within the time provided
- missing bits of information when given instructions
- frequent requests for repetition of information
- struggling to copy large amounts of material from the whiteboard
- being slow to provide responses in conversation or showing delayed reactions to comments
- difficulty keeping up in discussions or games
- getting easily overwhelmed when provided with tasks and showing frustration and/or disinterest.

Slow information processing speed can mean it will take your child longer to develop new skills and they may struggle to keep up with their classmates. Some simple strategies can help your child to better manage information, reduce the likelihood of overloading your child's cognitive system and minimise the confusion and frustration they may experience due to slower thinking skills.

'He just can't seem to keep up with tasks at school but when he has time to work through things at his own pace at home he does really well.'

- Parent of a seven-year-old leukaemia survivor

Strategies for dealing with information processing difficulties

For parents

- The most important strategy to help a child with slowed information processing speed is to provide information slowly with numerous repetitions.
- Break down activities into short step-by-step instructions and lengthy information into meaningful chunks.
- Keep instructions brief and clear. Example: Instead of a lengthy exchange with your child regarding the state of their room such as: 'Your room is always a terrible mess with clothes and toys everywhere. I want you to pick up all your toys off the floor and put them in the cupboard, get your dirty clothes in a pile for the wash, straighten up your bed and get ready for dinner.' Try to

- shorten your instructions to a handful of key points like: 'I want toys in the cupboard, clothes in the wash, bed done. Then get ready for dinner'.
- Whenever possible develop routines to help your child with common activities. If they are familiar with the sequence of steps involved in an activity it will be easier for them to focus on the specifics of the task at hand without having to carefully process all the information provided to them.
- Don't rush your child. They are generally not being lazy or difficult when they take time to respond to your questions or complete an activity or chore. Rushing them will increase the likelihood of mistakes and make them feel less competent at getting the job done.

For teachers

- Keep instructions short. Write key points on the board and repeat them. In the classroom it can be useful to have another student repeat instructions after providing them to the class. It may also be worth checking in with your student to see if they know what they are supposed to be doing.
- Reduce the workload for classroom tasks. Provide worksheets with fewer items than their classmates (for example,

seven comprehension questions instead of ten) to allow your student to complete their work within the time allocated.

- Provide extra time for take-home assignments. It is best to give your student the assignment before the rest of the class and allow them to hand it in on the same day.
- If your student is slow at copying information from the board, try providing handouts (written summaries of classwork and homework tasks). Other ideas include taking a photo of the board and being allowed to copy a friend's notes.
- Provide them with leading questions and regularly review the main points of classroom discussions.
- Write information on the board for your student to refer to during class as a prompt for tasks.

 Example: When discussing a book, draw an information tree on the whiteboard. This should label each of the key characters along with one of their defining features. Lines can then be used to show relationships between the characters and changes in situations over time. This can help children with slowed processing speed to follow lengthy conversations about the book.

Attention and concentration difficulties

Being able to focus attention on important information and maintain concentration for long enough to complete tasks are skills that affect all forms of thought and learning for children of all ages.

Poor attention is perhaps the most common problem reported by parents and teachers of school-aged children. Young children naturally have short attention spans and are easily distracted by irrelevant information. We must therefore always consider a child's behaviour in comparison with their same-aged peers to determine if they are showing excessive levels of inattention or hyperactivity. For some children with attention deficits, even mild problems can affect academic performance and friendships, making it an important area for remediation.

It is important to note that children can have difficulty focusing and concentrating on information for different reasons. For example, a child who is slow to process information can easily become overwhelmed when given lots of information to remember. This may cause them to disengage from activities, hence appearing to have a problem with attention. As many of these skills are closely related, the strategies described opposite will usually assist with both types of problems.

Strategies for dealing with attention and concentration difficulties

For parents

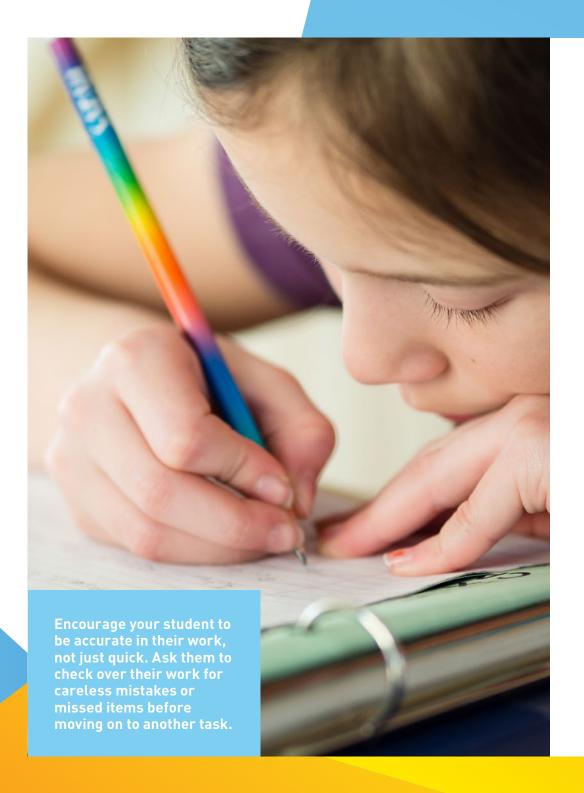
- Children can often look like they are listening to you but really their mind has wandered off. Therefore it is good practice to ask them to repeat instructions back to you or to explain in their own words what you've just said.
- At home, make sure the television, tablet or other items are turned off and put away during homework time to reduce distraction. If possible, let them work on a clean desk away from the bustle of the rest of the family.
- Have a homework plan that breaks activities into shorter tasks. Set an alarm clock at the beginning of a session to help motivate them to keep on task. Let them have a reward at each break (such as a play in the yard or a snack after 20-30 minutes of work). The use of tablets, computer games or phones is not advised for break times because it is usually difficult to disengage kids from these devices and refocus them to more mundane activities. So use them as motivators to complete their homework or chores instead and let them play with them when they are finished for the day.

For teachers

- Ensure you have your student's attention before giving instructions. This can be done by sitting them close to you and calling their name, or signalling to them with a hand gesture.
- Break long activities into shorter 5-10 minute tasks and provide step-by-step lists for your student to follow.
- Allow the student to take short breaks in between tasks to 'shake their sillies out'.

 Example: At school it is often beneficial to send them on an errand (for example, take a note to the office or empty the bin) in between classes to let them expend some energy and reset their concentration meter for when they return.
- Schedule more effortful activities at the beginning of the day and provide clear goals for tasks.

 Encourage your student to track their progress throughout the day by using a sticker chart or a list on a small whiteboard that can be marked and crossed out.
- When teaching new skills use objects of particular interest to your student to hold their attention.
 For example, use dinosaurs to instruct your student on math concepts. Use concrete, real-life examples when possible.



- Reduce distractions around your student in the classroom.

 Example: Primary school classrooms with artwork hanging from the ceiling or pencil boxes on desks can be particularly distracting. Sit the student near the front of the room to minimise what and whom they can see during class time.
- Use highlighters, asterisks, bolding or italicised writing to draw your student's attention to important items on worksheets and avoid using borders, pictures or other decoration.
- Give your student one activity to complete at a time and use prompts to remind them what they need to do when they switch to the next activity.
- Encourage your student to be accurate in their work, not just quick. Ask them to check over their work for careless mistakes or missed items before moving on to another task.
- Children often find it easier to focus and concentrate on topics when provided with pictures or images to look at and follow.
 Flowcharts and maps are particularly helpful when teaching complex material.

Working memory difficulties

Working memory refers to the ability to hold and work with information in your head. It requires the short-term storage of items for

mental manipulation and is often referred to as a mental notepad. That is, it is where you keep information while you are working on it, like when you are trying to calculate how much your grocery shopping will cost and how much change you will have, or when you need to hold on to a phone number in your head until you can write it down. Working memory is also necessary for continuously tracking conversations for details or actions that we use to update our own behaviour and verbal responses.

Strategies for dealing with working memory difficulties

For parents

- Teach your child to 'chunk' meaningful information together to reduce the burden on their memory system.

 Example: When trying to remember a phone number, teach your child to group the numbers into pairs (91827364 into 91-82-73-64). This means only four numbers need to be remembered rather than eight digits.
- A diary is a great way to manage homework tasks. You will need to prompt your child to write down homework activities given out during class and to check their diary each night.
- For children with a phone or tablet, the reminder function can be a handy way to set prompts for assignments and routines.

- A reminder checklist can be used to help children manage daily routines such as preparing their bag for school or organising their equipment for sports activities.
 Children often find this more interesting if they have taken part in developing the checklist so let them write it out in their own words and decorate it.
- Have a place at home where your child leaves their important belongings such as their keys and school bag. Ensure they place these items where they belong as soon as they get home so that they are ready for your child when they head off to school in the morning.

For teachers

- Provide written step-by-step instructions on the whiteboard or a worksheet to help your student keep track of what they should be doing.
- Encourage your student to have working out paper on their desk to assist with all tasks.
- Visual or concrete aides are helpful for children of all ages and should be kept close at hand.

 Example: When teaching children about fractions use an orange to demonstrate the concept and let them use the pieces to perform calculations. For young children, Smarties or Cheerios can be great motivators to do addition or subtraction sums, especially if you let them eat the counters

- when they get it right!
- Remind your student to write homework tasks in their diary.
 Having a clear pocket where they can place notes for parents or worksheets to take home can be very handy as well.
- Mnemonic strategies can help improve recall of information and can also be fun.

 Example: The mnemonic TELL can be used when teaching essay writing strategies. It stands for topic sentence, expand, lots of evidence and link.
- A very useful guide to working memory difficulties can be found at <www.york.ac.uk/res/wml/ Classroom%20guide.pdf>

Executive functions: planning, organisation, self-regulation and problem solving

Executive functions are the skills responsible for controlling and managing other thinking skills and behaviours. Executive difficulties can look quite different from individual to individual because there are many aspects to executive functions that develop at different ages.

Some common examples of difficulties with executive functions include:

- leaving things to the last minute and then being unable to complete tasks properly because they have run out of time or don't have the right tools available or organised
- their bedroom or locker always being untidy and disorganised (and as a result, they can never find what they need and are late to get to class or leave the house)
- bringing the wrong books to class or forgetting their sports clothes on sports day
- forgetting appointments, dates with friends or losing track of time when they are out

- their plot or ideas in essays and projects are often disjointed and difficult to follow
- finding it hard to think up different ways to solve a problem and often giving up if their first attempt or strategy fails
- saying inappropriate things or showing inappropriate behaviour at inappropriate times
- having difficulty getting started on tasks or knowing when to stop
- struggling to understand abstract or theoretical concepts
- finding it hard to generalise skills to new situations.

Executive functions are the last cognitive skills to develop and are not fully mature until adulthood. All children and adolescents will therefore have some difficulty: planning projects or social functions; organising their ideas or belongings; solving new problems quickly and without error; and monitoring their thoughts and feelings to ensure they act in a socially appropriate way. Some children show excessive difficulties in these areas and struggle to keep up with their peers. It is important to note that because

many of these skills are immature in young children, it is often not until a child reaches secondary school that we see these problems. This happens for two reasons. First, many of these skills undergo a period of major development during adolescence, and it is when a child fails to make the gains seen in their peers that the problem becomes evident. Second, there is a much greater demand placed on children in secondary school for selfmonitoring, planning, organisation, problem solving and strategy testing.

Strategies for dealing with executive function difficulties

For parents

- Routines provide important structure for children. Having well learnt routines for how to approach common tasks will help organise your child and minimise time wasting.
- Example: A morning routine will help your child get ready for school quickly and reduce the risk of them forgetting items (like their diary!). Some children will benefit from having routines written down for them and placed in a highly visible area as a prompt (such as a list of actions for packing their bag at the end of the day that is kept in their locker or desk). Younger children will work best with photo lists for new routines so take photos of your child performing each of the steps to getting ready in the morning and place these on some poster paper in the hallway as a guide.
- A diary is the easiest way to assist your child with scheduling activities. It works as a reminder and also a time management system. Having a 'to do' list that can be moved from day to day is also advisable. Your child may require prompts to check their diary in the morning and evening and parents and teachers should make a habit of regularly checking the diary to ensure they are using it correctly.

- Assist your child with designing a homework schedule. Make sure there are clear goals and priorities for all activities and that it notes when and where work will get done. Help your child work out how long tasks will take to complete and then work backwards to allocate appropriate time for your child to do this.
- Help your child brainstorm ideas for projects, essays or stories.
 Write these down on sticky notes or use a computer and then help them organise these into a logical structure.
- It is very useful to have a duplicate set of textbooks to keep at home in case your child forgets to bring home the right books for homework tasks.
- Provide clear instructions and outcomes for children who have difficulty controlling actions or speech. Be consistent, clear and uncomplicated in instructions and consequences.

For teachers

Many children at secondary school will require extra time to get from class to class. A 'buddy' to direct the student between classes when they first start Year 7 can be very helpful. It is important that the student is not punished repeatedly for lateness if they have trouble getting from class to class.



- Encourage your student to use a daily planner or diary to organise their time at school. Prompt them to write down homework tasks and help them map out work schedules for projects.
- Introduce the use of colour-coded folders and timetables with one colour for each subject. Example: Highlight all maths periods in the timetable in red and use red contact to cover maths texts. Some children find it even easier if they have a coloured tote bag for each subject that is colour-matched to their timetable. In this case the child would have a red cloth bag for their maths books that they would bring to class and then return with the texts inside to their locker at the end of the period.
- Planning sheets are a great way
 to help your student work out their
 approach to tasks. For example, a
 planning sheet for a story or
 essay writing would have boxes
 with headings and prompts for
 each of the elements required in
 an appropriate order.
- Encourage your student to write a draft for all lengthy tasks so you can discuss their ideas before they complete the larger document.
- When teaching new concepts do not assume your student will generalise this learning to other situations. They will require exposure to multiple situations or examples of when the skill can be used.

More resources for parents and teachers

For more information on attention, information processing and executive difficulties consider these resources:

- Organize your ADD/ADHD child: A practical guide for parents by Cheryl R Carter (2011). Although this book is aimed to assist children with attention deficit disorder, it has a number of great tips and techniques that can help children with mild difficulties in attention and information processing and can also be applied to children with executive difficulties.
- For more reading on executive difficulties and how to help children develop these skills, the book *Late*, *lost and unprepared:* A parent's guide to helping children with executive functioning by Cooper-Kahn & Dietzel (2008) is a useful resource

- The <www.projectlearnet.org>
 website is a 'brain injury' site
 but it provides lots of information
 and tips on the wide range of
 difficulties that children can have
 with thinking, learning, emotions
 and behaviours.
- The Ronald McDonald Learning Program website at https://learningprogram.rmhc. org.au/index.php> has a lot of useful information for parents and teachers regarding school challenges and resources for children.

Academic achievement following treatment for cancer

The cognitive late effects described in this booklet can affect new learning. Children are learning new things all the time, so even mild difficulties can have an impact on how they perform at school. They often miss periods of school because they are unwell or because they have to go to hospital. This can result in gaps in their knowledge. That is, missing 'building blocks' that are necessary for academic progress. So if we use the example of a race, some children returning to school following treatment will start the race behind their peers and will also be slower at getting around the track.

Slow academic progress is a major frustration for children and adolescents and is often difficult for parents and teachers to fully understand. Parents find it particularly difficult knowing how to help their child because they find that training in specific areas, for example, with reading, will help with that skill but not in other areas. As you have been reading this booklet you may have identified a number of difficulties in the learning areas

described that fit your child well. These may be the reason that your child is less efficient at developing new skills and making and keeping new friends. Tiredness, emotional and sensory issues can also make learning harder and play a role in slowed progress.

While many strategies have been described in this booklet it is best to identify a few areas to tackle at any one time and to try a handful of strategies to assist with those problems. Not all strategies will work for all children, so it is important to trial a number of them to see what suits your child best.

There are a number of other general strategies that are useful in the academic environment. They include:

 Set up an Individual Learning Plan. This will help document the student's strengths and weaknesses for all staff involved with their learning and set out some strategies that help them better participate in school activities.



- Structure, routine and providing step-by-step instructions are important for all types of challenges that students face. Have instructions placed on the board, routines written out as prompts in appropriate places and visual aides to assist children who may miss pieces of information.
- 3. Modifications to classroom tasks can be particularly helpful for a child who struggles to keep up with the amount of work provided in class. A reduced workload, extended time to complete activities, assistance from a helper or integration aide (where available) and visual or concrete aides will help most children. For older children and adolescents, audio textbooks and recorded lectures can also be very useful.
- 4. Test situations are particularly challenging for children with slowed learning. Provide extra

- time, offer oral instead of written exams, a scribe or let them use a computer or cheat sheets all these options can be discussed with the school. Depending on the age of your child some of these compensatory strategies may not be allowed.
- 5. Young children benefit from having a classroom aide or 'buddy' who can answer their questions or provide prompts. This may be particularly useful for transition times when new routines and subjects are being introduced.
- 6. Tutoring may be available through the Ronald McDonald Learning Program. A referral can be made by a parent, teacher, doctor or other staff member via the website at https://learningprogram.rmhc.org.au/index.php>

Other factors affecting academic performance

As indicated previously, a range of factors can influence children's and adolescents' learning and academic performance. In addition to cognitive late effects, children and adolescents who have been treated for cancer may have other effects of treatment that need to be considered when trying to optimise their potential for learning and their overall quality of life. The information in the following pages includes some factors you may need to consider for your child.

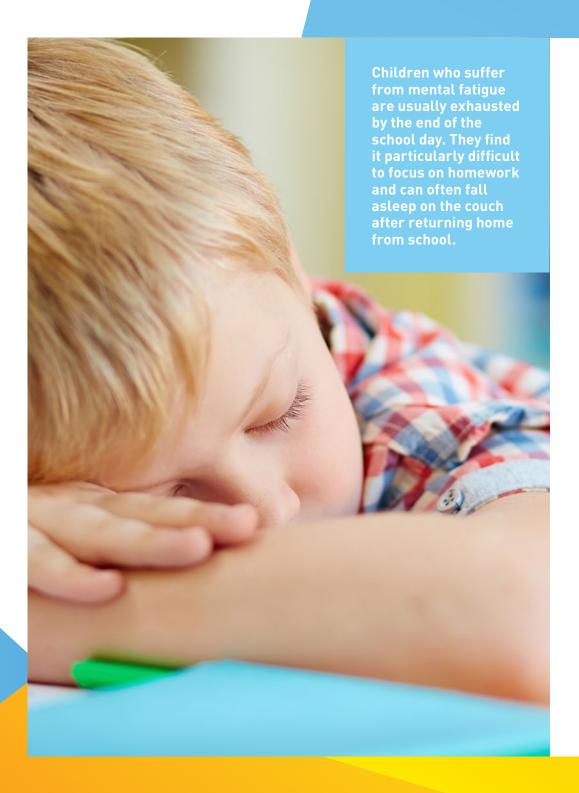
Fatigue (persistent tiredness)

What is fatigue?

For some children and adolescents, fatigue or persistent tiredness can be present long after treatment has finished. This tiredness can be the result of physical changes that have taken place because of your child's illness or treatment. Physical fatigue is generally easy to spot because it is usually accompanied by some form of physical impairment (for example, slow handwriting or unusual gait).

Simple strategies to reduce the amount of physical activity required by your child will assist with energy levels. For example:

- Children should be provided with handouts in class rather than asked to copy large amounts of information from the board.
- Two sets of books could be provided to avoid your child having to carry a heavy school bag to and from school.
- Older children will benefit from a locker closer to their main classroom.
- Physical education classes may require modification for these children with a reduction in high-intensity sports and allocation to other duties when possible (such as refereeing sports games, scoring or rest periods).



What does mental fatigue look like?

Your child may also be experiencing mental fatigue which is often harder for children to describe and for parents and teachers to identify. Mental fatigue can result from the extra effort required for a child with cognitive late effects to learn new skills. It affects the ability to focus and sustain attention and to process and recall information. Children or adolescents who show signs of fatigue are therefore at risk of missing or losing information due to tiredness. They may also seem irritable, restless or teary at times. Their behaviour might be mistaken for laziness or a lack of motivation.

Children who suffer from mental fatigue are usually exhausted by the end of the school day. They find it particularly difficult to focus on homework and can often fall asleep on the couch after returning home from school. Excessive mental fatigue can have a substantial impact on academic progress and may also interfere with social participation.

'She often falls asleep in the car on the drive home from school and when it comes to homework she can be irritable and disinterested.'

> - Mother of a nine-year-old lymphoma survivor

Strategies for dealing with mental fatique

For parents

- Make sure teachers know what to look for; for example, a child looking vacant, getting restless, yawning, slumping down on their chair or desk can all be signs of mental fatigue. Rest, not reprimand, is what these children need to perform at their best.
- Children who struggle with mental fatigue are often exhausted by the end of the school day and can become teary and frustrated when having to complete activities at home. A 20–30 minute power nap can help 'reboot' them before beginning their homework. In addition, make homework tasks fun, engaging and brief.

For teachers

- Short breaks throughout the day may be necessary. Building rest breaks into activities for the entire class is a good way to do this so that a child does not feel singled out.
- A change can be as good as a rest!
 Change activities every 30–40
 minutes to keep 'zoning out' to a minimum (every 20 minutes for younger children).
- Engaging in physical activities between tasks can help children refocus. Allow the student to move around the classroom, go outside for a drink of water or send them to the office on an errand.
- Young children may benefit from a quiet corner at the back of the class with a beanbag or cushions where they can take a short break during the day. Some children may prefer to visit the 'sick bay' for a short nap if possible.
- Where possible reduce homework loads. For secondary students, excusing them from a nonessential subject to work independently in the library or another space may help them complete homework in school time and improve the quality of the work they are able to produce.

Emotional difficulties

Some children and adolescents treated for cancer can experience periods where they may demonstrate behaviour problems, are more worried or stressed than other children their age or have periods where they feel down or unhappy. This can occur for many reasons including: the stressful nature of hospitalisation and cancer treatment itself; prolonged disruption to their normal activities (especially interactions with other children or peers); and/or strains on family relationships that commonly occur when a child is diagnosed with cancer.

What do emotional issues look like in children and adolescents?

In children and adolescents, emotional issues often look a bit different from adults. This is mainly because children find it hard to label and talk about how they think and feel.

It is important to remember that not all children or adolescents will experience these difficulties but, if they do, they will improve with some extra support from parents and teachers. If your child is experiencing any of these problems and they are getting in the way of their ability to function at home or at school, it is important to talk to a member of your child's healthcare team and/or school. For some children and adolescents more support is necessary in the form of a trained professional like a counsellor or psychologist.

Some common indicators that your child may have some emotions that are making them unhappy or stressed are:

- persistence of behavioural difficulties that may have arisen during cancer treatment such as tantrums, separation anxiety or irritability
- withdrawal from others, including school withdrawal or refusal
- physical complaints without any clear medical cause (such as headaches, tummy aches, tiredness or joint pain)
- poor sleep (such as not getting to sleep or frequent waking) and changes in appetite or eating patterns
- difficulty making friends or re-integrating with their friendship group
- apparent disinterest or loss of pleasure in activities they used to enjoy
- increased fearfulness about trying new activities
- excessive worrying about their health.

Adolescents and young adults who are experiencing significant hormonal changes may also show frequent and extreme mood swings. If you are not sure if your adolescent is experiencing more than just 'normal teenage mood swings', it is useful to think about how long the issues have been going on for and if they are still enjoying activities that they previously found fun and enjoyable. The website <www.raisingchildren.net.au> has some useful information on what are 'normal' behaviours for children of different ages that could help parents spot the difference between 'normal' behaviour and behaviours or emotions that may require extra support from a health professional.

What can I do to help my child if I think they might be experiencing difficulties emotionally?

- For older children and young adolescents, if they won't talk to you, try to make sure they have at least one good friend or teacher they can talk to who they feel 'gets them'.
- 2. Mentoring and having an older role model is a protective factor for mental health in young people. Look for someone at school or in your local community who can provide this kind of support.

Starting a new sport can be a protective factor to improve mood and foster selfconfidence through participation.



- 3. Sometimes younger children cannot express how they feel with words and so drawing a picture can help them to tell you how they are feeling. Getting them to draw what might 'make it better' or using feeling cards might also help you to understand how to help them.
- 4. Stress management, breathing, relaxation or meditation techniques for children and adolescents can be helpful when faced with performance anxiety and to improve sleep at night (see websites opposite).
- 5. Starting a new sport can be a protective factor to improve mood and foster self-confidence through participation.

What can I do to build my child's social skills and confidence?

- In younger children balancing your child's needs and incorporating time for healthy childhood activities (such as socialisation and play) is very important.
- 2. Encouraging your child and building on their individual strengths and competencies (for example, drawing, dancing, music or sports) is helpful in building a healthy self-image and boosting confidence.
- 3. Try to use positive language during tasks or homework.
- 4. Always give your child the message 'I believe in you'. This is the most powerful intervention you can provide as a parent.

Where can I go to get more help and advice?

- 1. Organise for your child to visit the school counsellor or psychologist.
- 2. Visit your general practitioner and ask for a mental health plan under the Better Access scheme (this provides Medicare rebates for mental health support) to access a community psychologist or counsellor for your child or adolescent (up to ten sessions a year).
- 3. CAMHS (Children and Adolescent Area Mental Health Services) provide support for children or adolescents experiencing more complex and severe mental health conditions. Visit <www.health.vic.gov.au/mentalhealth/services/child/index.htm>
- 4. The Kids Helpline is a confidential and 24-hour phone counselling service. Phone 1800 155 800 or visit <www.kidshelp.com.au>

- 5. Headspace provides online resources for young people aged 12–25 who may be experiencing mental health difficulties. They also have local centres you can visit. Visit <www.headspace.org. au> for more information and locations.
- 6. beyondblue provides online resources for lowered mood and depression in all ages. Visit www.beyondblue.org.au
- 7. The youth section of <www.anxietybc.com> has some great resources for young people to help with stress management.

Where can I go for further information?

Your child may be eligible for an educational assessment through their school. Discuss this with their teacher, welfare officer or principal. Many hospitals have a long term follow-up program or a late effects clinic. In Victoria, the Long Term Follow-Up Program (LTFP) is coordinated and supported by the Paediatric Integrated Cancer Service. Many of the LTFP clinics have a neuropsychologist in attendance who will be able to provide advice, intervention and support. You can contact the LTFP in Victoria on [03] 9345 9512.

To google or not to google – sometimes that is the question!

The internet is awash with information for any question or problem you might want to know more about. Some websites are very useful but many are just people chatting about things they might think they know about (much like 'old wives tales' in an earlier time). So we like to warn parents to be aware that 'Dr Google' can often give the wrong diagnosis or unsupported advice that might seem to fit your child's problems. While most information is not

harmful, using the wrong strategies to address your child's difficulties can cause frustration and distress, and some can be costly and time consuming without reward.

Here are some websites that provide helpful, clear information on child development, parenting strategies and resources for assisting young children to meet their developmental milestones. They are not specific to children who have been treated for cancer but address the types of problems discussed in this booklet:

- www.raisingchildren.net.au
- www.rch.org.au/ccch/ resources_and_ publications/Parent_fact_ sheets/
- www.cdc.gov/ncbddd/ childdevelopment
- www.kidsmatter.edu.au



The very basics!

Some children who have been treated for cancer can experience difficulties with learning and behaviour. The most common problems are:

- being slow to process information and complete work
- finding it hard to concentrate for long periods and are easily distracted
- often forgetting information or get mixed up about the order of tasks
- becoming easily fatigued and often irritable.

Here are five key strategies to help your child if they are showing these kinds of difficulties:

- Give one instruction at a time. Make it short and clear.
- Repeat information as often as necessary.
- 3. Show them what to do. Don't just tell them.
- Use exciting, child-friendly objects and topics to get their attention and keep it!
- 5. Reward good behaviour rather than punishing bad behaviour.



Learning can be hard work!

Some children who have been sick for a long time can find it hard to keep up with other kids their age. This might be because you feel tired during the day, it seems that the teacher is talking too fast for you to keep track or you might forget instructions even when you try really hard to listen. There might also be times when you don't know what the teacher is talking about because you were not at school when the other kids in your class learnt about it.

When learning is hard you might need extra help from your teacher or parents to do your work. It is important to remember that everyone has their own way of learning and there are things you will be good at and other things that might take you extra time and effort. Writing these things down can help you talk to your parents and teachers about them so you can get help when you need it, and also have activities to show what you are best at. Use the table below to make your own list to bring to your parents and teachers:

Things I'm good at	Things I find hard to do	Things I'd like to learn or do better	Superhero powers I would love to have!

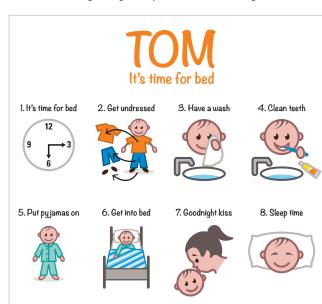
You might choose one thing you find hard to do to work on each month (although some things might take much longer than others). You can organise a plan with your parents or teachers with some goals set out for each week. You might also work out some rewards (like a visit to your favourite park or a day out with your friend) for when you reach your goals.

Can you do it on your own? ...Yes you can!

Keeping track of what you are doing can be tricky. To stop you getting in a muddle and having to keep asking your parents or teacher for help an activity chart might help you do it on your own. You can make it yourself or ask your parent or teacher to help you make one for the activities that you find hardest to do.

A great one to start with is your bedtime routine. You can draw pictures of the tasks you have to do, download them from the internet or take photos of yourself doing them! Then you can arrange them on some paper or card, number them and decorate them. If you are really lucky you might be able to laminate the card (put some plastic over it) at school or have your parents do this for you. You can then cross off or tick the tasks when you finish them at night so you don't skip any by mistake.

Here's what a 'getting ready for bed' chart might look like.



You can make charts for any activity where you need some extra help to remember all the steps. Making one with your friend or brother or sister can be lots of fun.

What is this feeling?

We can all have times when we might not feel like playing with our friends, or we start to cry, scream, laugh uncontrollably or we get in trouble from our parents or teachers. We might not even know why we are acting this way or how we feel at the time. Keeping a 'feelings journal' can help us learn about what is happening when we act in different ways and what makes us most happy.

Writing in your journal every day about what has happened is the best way for you to learn about how you feel and act. It can also be a good way to talk to your parents or teachers about how you feel and what might help you get more positive feelings (the ones that make you feel good) and less negative feelings (the ones that make you feel down).

Here is an example of a page from a feelings journal. You might like to make your own using an exercise book or diary, and decorate it with drawings or photos.

Feelings journal Date: Today I felt: Sad Overwhelmed Нарру Angry Relieved Bored Jealous Tired Left out Proud Disappointed Lonely Afraid Relaxed Embarrassed Worried Excited Calm Confused Silly Sad Angry Overwhelmed Нарру What happened today that caused this feeling? For positive feelings, what can I do to keep this feeling or cause it again?

If you find you feel sad or angry most of the time it is important to talk about it with someone you trust. Your parents and teachers are there to help you be the best you can be, so let them know if you are having a hard time feeling good about things and about being you.

Useful contacts

Long Term Follow-Up Program

Phone: [03] 9345 9152

Email: ltf.program@rch.org.au

Writing in your journal every day about what has happened is the best way for you to learn about how you feel and act.



Useful websites

Paediatric Integrated Cancer Service (PICS)

www.pics.org.au

Australian Cancer Survivorship Centre (Peter MacCallum)

www.petermac.org/about-us/ australian-cancer-survivorshipcentre

Australian Psychological Society (click on 'Find a Psychologist')

www.psychology.org.au

Cancer Council Victoria

www.cancervic.org.au

Children's Cancer and Leukaemia Group (United Kingdom)

www.cclg.org.uk

Cure Search for Children's Cancer (The Children's Oncology Group, North America)

www.curesearch.org

Hope portal – a website of recommended childhood cancer internet resources developed by the Children's Hospital Los Angeles

searchhope.chla.org

LIVESTRONG Foundation (North America)

www.livestrong.org

Monash Children's Hospital

www.monashchildrens.org.au

The Royal Children's Hospital

www.rch.org.au

The Children's Cancer Centres' Parents' Advisory Group

www.rch.org.au/ccc/pag

Victorian Department of Education and Training

www.education.vic.gov.au

The Centre for Working Memory and Learning, University of York

www.york.ac.uk/res/wml

LEARNet - Problem-solving system and resource website

www.projectlearnet.org

Victorian Department of Health and Human Services – Mental health services

www.health.vic.gov.au/
mentalhealth/services/child

The Kids Helpline

www.kidshelp.com.au

headspace

www.headspace.org.au

beyondblue

www.beyondblue.com.au

Anxiety Disorders Association of British Colombia

www.anxietybc.com

Ronald McDonald™ Learning Program

https://learningprogram.rmhc.org.au

Centres for Disease Control and **Prevention**

www.cdc.gov/ncbddd/ childdevelopment

Raising Children Network

www.raisingchildren.net.au

KidsMatter

www.kidsmatter.edu.au

Other resources

There are a number of publications available about childhood cancer. Please ask your nurse coordinator or healthcare team about access to these books or for further information. These booklets are available on the PICS website at <www.pics.org.au> Other information booklets in this series are:

Learning curve: education and socialisation after childhood cancer

An information booklet for children, parents and teachers

Preschool (kindergarten) to prep

Learning curve: education and socialisation after childhood cancer

An information booklet for adolescents, parents and teachers Senior secondary school





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