Paediatric Integrated Cancer Service

A statewide cancer service for children

Preschool (kindergarten) to prep

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
Preschool (kindergarten) to prep
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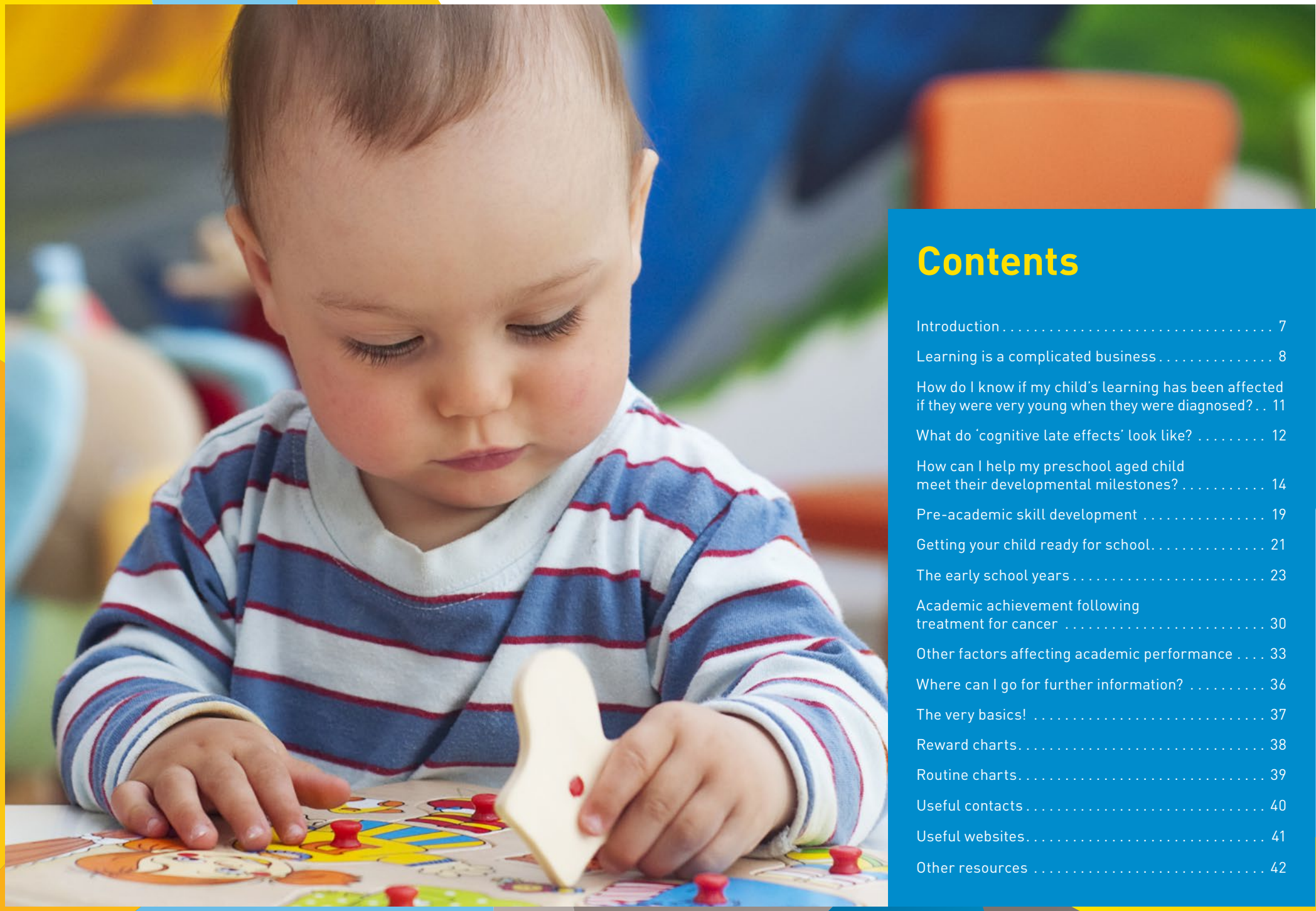

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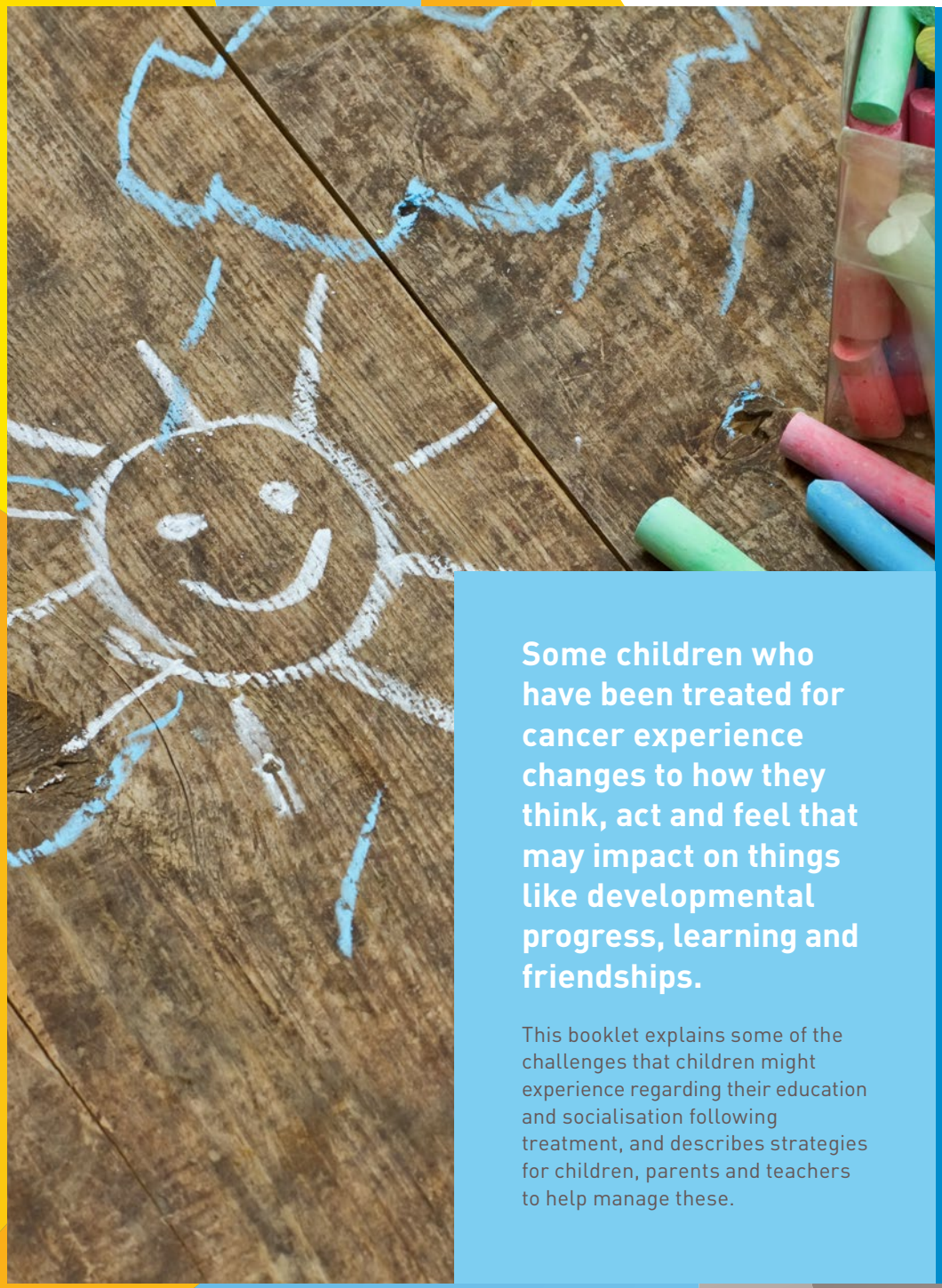


Some children who have been treated for cancer experience changes to how they think, act and feel that may impact on things like developmental progress, learning and friendships.

This booklet explains some of the challenges that children might experience regarding their education and socialisation following treatment, and describes strategies for children, parents and teachers to help manage these.

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 activities.

'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 and address the thinking, learning, 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.

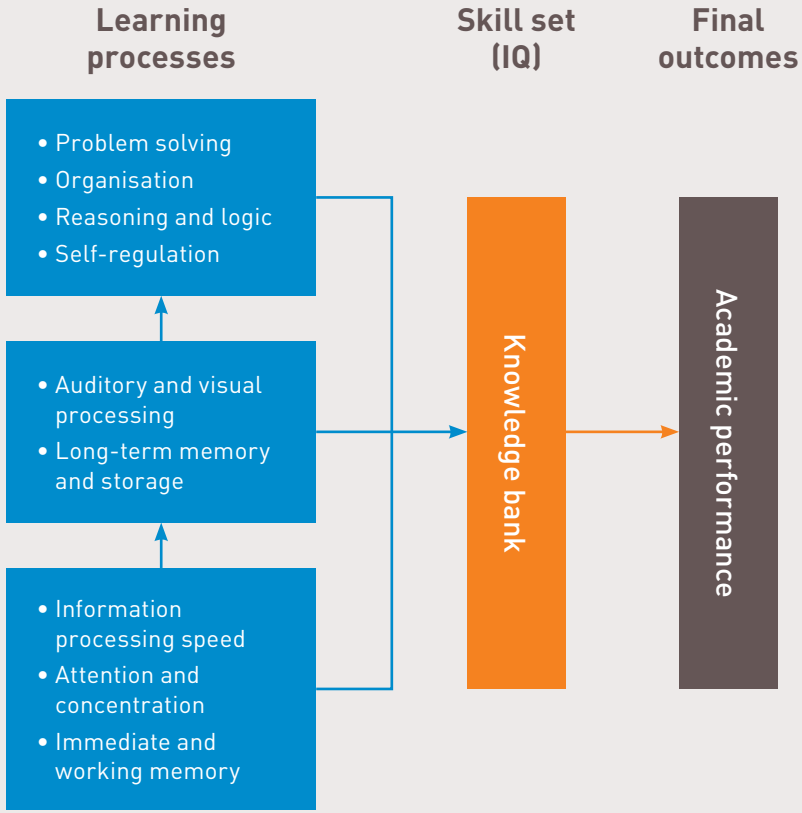
Children diagnosed at a very young age have had limited time to explore and interact with their environment. They are often physically restricted during periods of illness and spend much of their time around adults rather than other children their age. They may also be less willing to engage in unfamiliar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

Some children may also have experienced a period of regression of newly developed skills in the early stages of illness. For example, a child who has just started to talk may not use any words for some months, or a child who is taking their first steps might return to crawling for some time. There may also be a delay in acquiring milestones that are yet to develop and some children may show uncommon patterns of development if they have been hospitalised for extensive periods.

Despite these altered experiences, most children will show developmentally appropriate skills once they are well enough to engage in daily activities and return to their community of little people. Children learn best from watching other children their age, so providing them with opportunities to play and enjoy activities that develop their knowledge base is the best way to encourage their progress and put them on a level playing field with their peers.

Nothing brings greater joy to a parent than watching their child master a new activity. In the same way, having a child fail to learn a new skill after repeated teaching can be very frustrating. Multiple cognitive abilities are required to learn even the simplest tasks and a child who is struggling to meet their developmental milestones may be experiencing difficulties in one or a number of areas.

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.



As many of these cognitive processes are still immature in young children, you may not notice difficulties in these domains until long after your child has completed treatment, at a time when new skills are due to come 'on line'. Monitoring your child's progress over time is therefore very important as their needs and strengths will likely change as they age.

Impairments in physical, sensory or emotional areas can often look the same as the thinking difficulties described previously. 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.

A number of other factors may also contribute to your child's ability to explore and engage in learning opportunities 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).

How do I know if my child's learning has been affected if they were very young when they were diagnosed?

All children, regardless of their medical history, have strengths and weaknesses in their thinking skills and act differently in various situations. 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. Some children enjoy new experiences and meeting new people, while other children are more reserved and prefer to be in familiar environments with people they know.

It is difficult to know how your child would have developed if they were not diagnosed with cancer and whether there has been an alteration to their path as a result of the disease or treatment. In regard to helping a child who is experiencing difficulties, it does not matter how the problems developed but rather that you have a good understanding of your child's learning style and what holds their interest when teaching new skills.

Understanding how your child best takes in information and remembers it will help you choose strategies that work to their strengths and helps them achieve to the best of their potential. This may not be the same level as their peers, so using their own performance as a benchmark for improvement and setting realistic goals will help them experience success and motivate them to try...try...and try again.

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. Some children who have had cancer will therefore 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. Rather they will 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. As your child gets older you may notice difficulties in other areas such as essay writing or other skills that are developing at that time.

'I didn't realise he was having trouble until his preschool teacher raised concerns about his ability to learn new games and follow instructions. I just thought that was how a four-year-old did things and we didn't have many kids his age around to compare him to because he was in treatment for so long.'

– Mother of child treated for leukaemia

Because of the type of difficulties with learning processes that can occur following cancer treatment, many parents do not become aware of these problems until their child has started preschool or primary school. This is understandable given that many of these thinking skills are still immature in young children.

After all, almost any parent of a three-year-old would say their child has trouble following instructions and are highly distractable! It is often only when children start to struggle with language development and early literacy skills that concerns are raised.

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

- Does my child have trouble following simple instructions on a daily basis?
- Does my child use fewer words or shorter sentences than other children their age?
- Does my child take longer to do routine tasks and constantly need reminding of the order of activities (like getting dressed in the morning)?
- Is my child more distractable and forgetful than their friends?
- Does my child show very different behaviours from other children their age?

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. Please also note that for the purpose of this information booklet, the term 'preschool' refers to any early childhood learning program that your child may attend before primary school, including kindergarten.

How can I help my preschool-aged child meet their developmental milestones?

The major developmental tasks during the preschool years are language and motor development, as well as socialisation skills. These skills generally develop naturally and rapidly without requiring intervention. However, for children who experience cognitive late effects in learning processes, acquiring these skills can require extra effort and support for them to meet their full potential.

Let them play!

Playing is a young child's full-time job. Allowing your child to work at this is perhaps the most important strategy to encourage development of these skills in your child. In particular, group play environments such as play group and preschool provide a great opportunity for children to engage in developmentally appropriate activities with their peers. Play groups are available for toddlers, preschoolers and their parents or caregivers. They encourage skill development by allowing toddlers to practise physical, intellectual and language skills, and preschoolers to practise socialising with same-aged children and engage in structured activities. Play groups in your area can be found at <www.playgroup.org.au>

Preschool provides an important introduction to primary school for all children. It is even more important for children who have experienced disruption during early life because it provides the stimulation and challenge required for brain development, encourages independent play and instils confidence and self-efficacy. Preschool enrolment is organised through your local council and various deadlines apply. Information on preschool programs in Victoria can be found at <www.education.vic.gov.au/childhood/parents/kindergarten/Pages/default.aspx>

Slow it down

Slowed processing speed is the main difficulty with thinking that children experience following treatment for childhood cancer.

'Information processing' refers to the ability to take in and manage the information collected by our senses, a skill that is important for all forms of thinking and behaviour. When a child is slow to process the things they hear and see, they can become easily overwhelmed and confused. This means they often 'switch-off' and miss bits of information.

The best way to help a young child with slowed processing speed is to slow things down and keep things brief. So:

- Give instructions one at a time.
- Make instructions simple and clear – avoid lecturing!
- Repeat, repeat, repeat!
- Stop at regular intervals to talk to your child about what they are doing or watching to help them rehearse this information.
- Ask your child to repeat back to you what you have said to make sure they have not missed any information.
- Give them plenty of time to complete activities.
- Ask your child to explain pictures or stories to you. This encourages deeper processing of the information and will allow them to 're-process' the content for better understanding.

Get their attention

All young children can be inattentive, fidgety and distractable at times. Yet they can watch their favourite show on loop for an hour without moving! Cancer treatments can result in attention inefficiencies but these difficulties can be hard to identify because children do not appear unusually hyperactive or difficult to control; instead, they have trouble focusing attention on important information and maintaining concentration. So while it might look like your child is concentrating, you might find that they have not taken in any information.

There are a few key strategies that can help:

1. Call your child's name or physically hold their shoulder when you need to talk to them. Being close and maintaining eye contact is particularly important.
2. Remove distractions. Don't expect that your child can ignore something (like the TV) because you have told them to. So turn off the music in the car, take away their tablet or remove the pencil from their hand before giving them instructions.
3. Keep activities short and highly motivating. This is particularly important when trying to teach them something new. Tasks should generally be broken down into no longer than 5-minute

segments and short breaks might be needed every 15-20 minutes.

4. Keep it clean! The 'work area', for example a bench-top, piece of paper or child's table, should be clear of any unnecessary items or decoration when you are trying to get your child to complete an activity.
5. Encourage your child to take their time when completing a task rather than rushing through and making mistakes.
6. Get your child in the habit of checking over their work. This allows for revision of the material and promotes good work habits for when they reach school age.
7. Using concrete objects that are of interest to your child to explain activities can sometimes help maintain their attention for longer periods. For example, use their favourite toy to demonstrate the steps for getting dressed.

Show them how

For children with working memory difficulties, the act of holding information in their head and using this to guide their actions is particularly tricky. They really need the information available at all times for them to check and revise what they are doing. As most children this age cannot yet read, pictures are the best way to help them hold, learn and track information.

This can be done in several ways:

1. As a first step, showing your child how to do something rather than just telling them will be of great benefit. Let them copy each step you show them a couple of times to help reinforce the task and the sequence of steps involved. Making a little video clip of the activity and using some of the available apps (for example, 'Clips' is a very simple and easy one to use) to make it cool and fun can also be a good way to get your child motivated and keep them on task.
2. Reward charts or routine charts can be particularly useful for teaching common routines. The chart will need to show the order of the steps required for the child to complete the activity with clear, large pictures. Young children generally love looking at themselves, so using photos of your child completing those activities can be a great motivator and will make the routine more relevant for them. Children also enjoy showing their progress, so if possible make the chart so they can mark off each step as they complete it. This can be achieved, for example, by: laminating the card so the child can mark it; using Velcro dots with a tick or a 'thumbs up' attached; or using 'windows' so they can be closed when a task is completed. An example of reward chart and routine chart can be found on pages 38 and 39.
3. Get their favourite toy or a good friend to do it with them! Sometimes using a favourite toy or a friend to demonstrate the steps of a task can help maintain your child's attention and make them feel supported when attempting something new and challenging.

Reward good behaviour

It can be extremely difficult to discipline an ill child. Understandably, establishing rules and boundaries often gets overlooked when children are struggling to cope with medical procedures, pain, physical restrictions and the many other challenges they face. When they finally reach a period of wellness, children who have been ill can sometimes have difficulty managing their actions and knowing what behaviours are appropriate in different situations. Young children in particular need their parents to provide clear rules and boundaries to help them do this successfully. It is important to remember that you are actually helping your child when you establish clear guidelines on how to act and what to say because they are too young to work this out on their own. Helping them manage their behaviour will increase success with their peers, improve family harmony and increase their sense of self-control.

Here are a few tips that can help get you started with managing problem behaviours:

1. Children respond better to reward than punishment. So make a big deal when they do something well or show positive behaviours without prompting. Clap, smile, do a dance – anything to make them know that good behaviour gets your attention and works in their favour. When possible, ignore problem behaviours and do not reward your child when they act in this way. For example, if your child throws a tantrum when denied a particular food, resist giving them the food to stop the tantrum. Instead, use the food as reward when they ask for it properly.
2. Be a role model. Model appropriate behaviours for your child. It is not enough to tell them how they should act – they need to see you do the same to reinforce the idea.
3. Choose one behaviour to tackle at a time. Children can feel overwhelmed when parents try to impose multiple new rules at once. This can have the opposite effect of causing resistance and increasing conflict.

Make their reward a trip to the park, the library, a cooking session, an extra hour they get to stay up one night or some other activity they enjoy.

4. Let your child have a say. Talk to them about the behaviours that are causing problems and let them help you choose one to focus on. Make this the target for a fortnight or month. Clearly lay out what behaviour you want to see and what the consequences will be for such behaviour.
5. Use a reward chart for the goal behaviour. Make it big, colourful and put it up in a prominent area of the home where it can be celebrated. Write out the goal to remind everyone of the target and decide on how many times your child must show the behaviour in order to gain a reward. You can use stickers to mark off target behaviours or you can get creative and make the chart a frog (magnet) jumping on lily pads to get to the reward, or a rocket bursting through asteroids to reach a planet. For more information visit <www.raisingchildren.net.au/articles/reward_charts.html>
6. Make the reward sustainable. Toys, electronics and so on can be expensive and generally lose their pulling power after a while. Children sometimes misbehave to get attention, so it can sometimes work in your favour to reward good behaviour with your attention and time rather than a gift. Make their reward a trip to the park, the library, a cooking session, an extra hour they get to stay up one night or some other activity they enjoy.

These strategies can also be used to target behaviours such as co-sleeping and bed-wetting. For any target behaviour you choose it is important to first rule out that it is not being caused by a medical, physical or intellectual issue.

Pre-academic skill development

If your child is experiencing difficulties in any of the thinking skills or behaviours described previously, these may impact on the development of language and motor skills. The strategies described will help them process and store information, but your child may also require additional support to reach language and motor milestones.

Language and pre-literacy skills

Language and pre-literacy skills are particularly important for school success. By the time a child has reached three years of age they should start to understand how objects are used, follow directions, use three- to four-word sentences and enjoy telling stories and asking questions. By four years old, children can often ask questions about who, what and why, use 900 words and speak in four- to five-word sentences that are mostly grammatically correct. They also start to become familiar with books and letters, are able to share ideas, and speak clearly enough to be understood by most people. The best way to encourage language development is to read to and with your child. This does not just have to be books but can include signs, packets, comics or toy instructions. You can role-play situations with them, like going to the shops, and introduce new words that way.

The following websites have more detailed information on what language skills your child should be demonstrating and some tips and games to encourage language development in preparation for school:

- www.asha.org/public/speech/development/Parent-Stim-Activities.htm
- www.dystalk.com/talks/64-top-tips-for-preschoolers-develop-your-childs-language
- www.getreadytoread.org/early-learning-childhood-basics/early-childhood/understanding-language-development-in-preschoolers
- www.pbs.org/parents/education/reading-language/reading-milestones/preschooler-language-development-milestones/

If your child is having significant problems with language development they may benefit from assessment and intervention from a speech pathologist. This can be discussed with their treating team at your next appointment.

Motor skills

Motor skills refer to both gross motor (such as walking, climbing and balance) and fine motor (such as writing, using cutlery and threading) skills. Children can display difficulties in one or both of these areas. The best way to develop your child's gross motor skills is to play games. For instance, Simon Says or Hokey Pokey, or activities that include kicking balls, balancing on each leg or dancing.

Other examples are throwing bean bags into washing baskets or over ropes and running to chase bubbles. You can get your child to imitate the way certain animals walk. It's even more fun if you join in! They can slither like a snake, hop like a bunny, waddle like a penguin, walk like a dog and spring like a kangaroo. Getting out to the park is one of the best ways to encourage gross motor practice.

Another option is classes at a local activity centre (for example, GymbaROO). These classes involve one-on-one focused play between a caregiver and child to promote early childhood development. More information can be found at <www.gymbaroo.com.au>

There are many fun and cheap activities that can help develop a child's fine motor skills. Drawing and painting are particularly important as preparation for handwriting skills, so try to include these activities in your daily routine. Other activities include playing with playdough, screwing and unscrewing lids on bottles, putting coins in a money box, building towers with blocks, stringing beads and connecting Lego pieces. Computer games can also help improve hand–eye coordination and can be used for brief periods.

The following websites have fun activities for you to enjoy with your child:

- www.preschoolactivitybox.com/preschoolfinemotorskills.htm
- www.skillbuildersonline.com/SBA/Catalogue.asp?Current=Fine+Motor+Skills

If your child is having significant problems with motor development they may benefit from assessment and intervention from a physiotherapist or occupational therapist. This can be discussed with the treating team at your child's next appointment.

Visit a few schools with your child. Talk to the teachers and other parents and see which one feels right for both of you.

Getting your child ready for school

Starting school is a major milestone for children and parents. School readiness depends on a number of factors including language, social, cognitive and motor skills as well as emotional maturity. You can help prepare your child for this big step in a number of ways.

Preschool provides the best preparation for starting primary school and is compulsory for four-year-old children in some states. It introduces a structured learning environment with a teacher and allows interaction with other children of the same age. Preschool teachers are well placed to monitor and identify areas of concern regarding learning and behaviour, and will be able to provide guidance on school commencement and support services that may be appropriate if your child is experiencing difficulties.

The following websites cover areas that are considered when determining whether a child is ready for school.

These include considerations such as: Can your child speak in sentences that can be generally understood? Can they cooperate and initiate conversations with other children? Can they hold a pencil correctly? Can they name shapes and colours? and Can they listen to a story?

- www.education.vic.gov.au/school/parents/primary/Pages/prepare.aspx
- www.eduweb.vic.gov.au/edulibrary/public/commrel/backtoschool/welcomeprimary.pdf
- www.kidspot.com.au/Back-to-School-For-parents-Is-your-child-ready-to-start-school+3926+153+article.htm

So they are ready for school…but which one? Some things to consider when comparing schools are:

1. Fatigue can persist for years after cancer treatment and you might find that your child still tires easily and naps during the day. Practical considerations such as choosing a school close to home, without stairs and on a small campus can help to minimise fatigue.
2. It is worth asking about the availability of learning support, a school psychologist or counsellor, the use of Individual Learning Plans (ILP) and frequency of Program Support Group (PSG) meetings.
3. Children generally transition better if they start school with someone they know. You might consider discussing school options with other preschool parents.
4. Visit a few schools with your child. Talk to the teachers and other parents and see which one feels right for both of you.
5. Involve your child in the process of choosing a school and get them excited about it!

The early school years

The early school years should be fun and exciting. Like little explorers, children set off every day to learn something new about themselves and the world – a wonderful, albeit exhausting, adventure. For a child experiencing cognitive late effects, there will likely be a few extra hills to climb along the way, making the process more effortful, tiring and frustrating. Below is a description of the type of difficulties your child may display in their first couple years at school and some simple strategies to help manage these.

Information processing skills

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 because it affects the amount and quality of the information a person can manage at any one time.

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

- difficulty following more than one or two instructions
- confusion about what they should be doing
- struggling to complete activities in the allocated time
- trouble keeping up in games
- failing to respond to questions.

Slow information processing speed can mean it will take your child longer to develop new skills and keep up with their classmates. Some simple strategies can help your child to process, store and manage information more efficiently, thereby reducing confusion and frustration.

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.

Strategies for dealing with information processing difficulties

For parents

- Make instructions short.
- Use clear, simple language.
- Repeat, repeat, repeat.
- Break long activities up into short step-by-step tasks that take no longer than a few minutes.
- Ask your child to repeat instructions back to you to make sure they have processed them.
- Develop routines for everyday activities. If your child is 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.
- 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

The recommendations made for parents apply equally well to the classroom.

- Repeat instructions frequently.
- Show the child what to do rather than just telling them.
- Use pictures or charts as a prompt for the child when completing activities.
- Sit the child next to a 'buddy' who can provide direction when necessary.
- Routinely check in with the child to ensure they know what they should be doing.
- Provide tailored worksheets with fewer items on them to allow the child to complete these in the same time as their peers.

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 to 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.

Attention problems most often present as:

- struggling to stay on task
- often missing information and not knowing what they should be doing
- talking when they should be listening
- starting activities without waiting for instructions
- frequently getting out of their chair.

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 below 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.
- Remove distractions. Don't expect that they can ignore something (like the TV) because you have told them to. So turn off the music in the car, take away their tablet or remove the pencil from their hand before giving instructions.
- Keep activities short and highly motivating. This is particularly important when trying to teach them something new. Tasks should generally be broken down into no longer than 5-minute segments and short breaks might be needed every 15–20 minutes.
- Keep the work area clear! Remove any unnecessary items or decorations from the area you are using and when possible use a room away from the rest of the family when teaching something new.
- Encourage your child to take their time when completing a task rather than rushing through and making mistakes.
- Get them in the habit of checking over what they have done. This allows them to revise the material and promotes good work habits.
- Using concrete objects of interest to your child to explain activities can sometimes help maintain their attention for longer periods. *Example: Use their favourite toy (such as Buzz Lightyear) to demonstrate the steps to getting dressed.*

For teachers

- Get the child's attention (through eye contact, calling their name or a hand signal) before giving instructions.
- Sit them close to the front of the class or near you when sitting on the floor. This will minimise what and who they can see and make it easier for you to redirect their attention when needed.
- Minimise distractions around the area where they are seated (such as pencils and papers on desks or artwork hanging in front of them).
- Check in with the child frequently to keep them on task.
- Break long activities into shorter 5–10 minute tasks and provide step-by-step directions for the child to follow.
- Allow the child 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 effortful activities for the beginning of the day when the child is fresh and enthusiastic.
- Use concrete aids when introducing new concepts and select items that are of particular interest to the child.

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 the continuous tracking of conversations for details or actions that we use to update our own behaviour and verbal responses. These skills are immature in young children and do not reach adult levels until well into adolescence. It can therefore be difficult to determine at this stage if your child does show reduced skills in this area.

Problems with working memory most often present as:

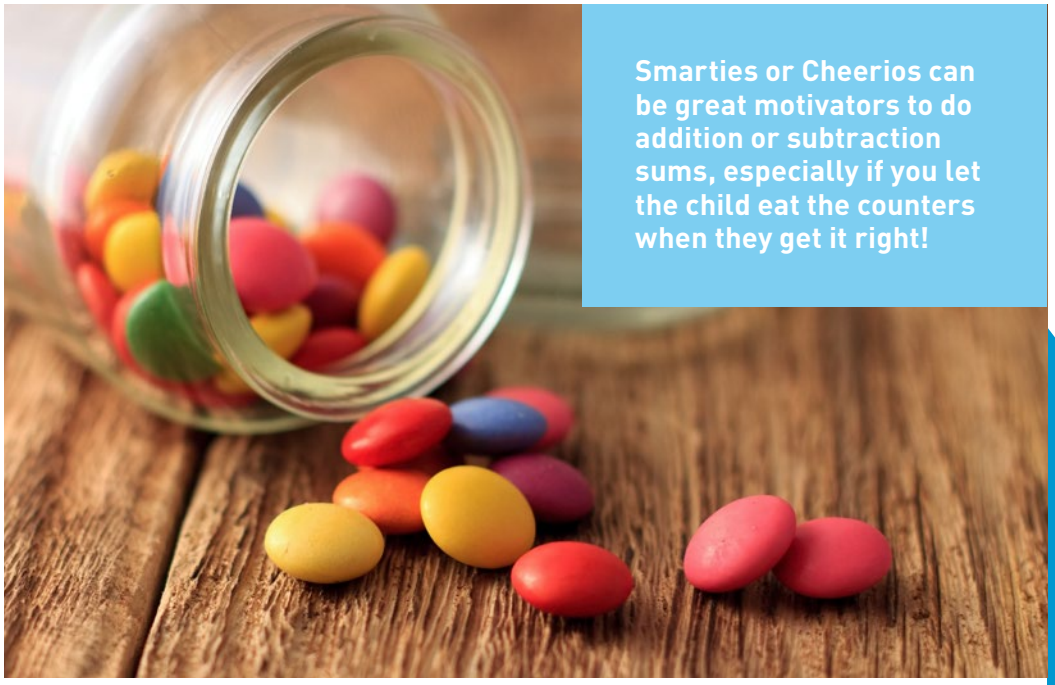
- difficulty following more than one or two instructions (in particular, your child is easily confused about the order of steps in an activity and often misses bits of information)

- trouble 'sounding out' words – this occurs not because of specific problems with literacy but because the child cannot hold the sounds simultaneously in their head and maintain them there to string together into the word
- not being able do mental calculations without using their fingers or objects to count
- not enjoying watching movies or lengthy TV shows
- often forgetting where they put things
- highly variable performance (for example, fluctuations in performance level from day to day or between tasks)
- often appearing inattentive and distractable.

Strategies for dealing with working memory difficulties

For parents

- Give one instruction at a time and prompt your child if they lose their way.
- If your child can read simple words write down lists for them to follow. As their own writing develops encourage them to write things down to remind them of activities they need to complete.
- Revise information for your child while reading a book or watching a show. They may have difficulty tracking the course of events or updating changes in plot.
- Teach your child to use memory strategies to reduce the load such as associating a person's name with a prominent feature.
  Example: Mr Barry has a beard ('Bearded Barry').
- 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 use pictures of them to demonstrate what needs to be done or let them decorate the list.
  Example: A morning routine will help your child get ready for school quickly and reduce the risk of them forgetting things. Younger children will work best with photo lists for new routines (for example, 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).
- Have a place at home where your child leaves their important belongings such as their school bag or library books. Ensure they place these items where they belong as soon as they get home so they are ready for your child when they head off to school in the morning.



Smarties or Cheerios can be great motivators to do addition or subtraction sums, especially if you let the child eat the counters when they get it right!

For teachers

- Keep information visible and accessible for the child to refer to while completing a task. Use picture charts and diagrams as much as possible to accompany verbal instructions.
- Visual or concrete aides are helpful for children of all ages and should be kept close at hand.
  Example: Smarties or Cheerios can be great motivators to do addition or subtraction sums, especially if you let the child eat the counters when they get it right!
- Compensatory strategies like using fingers to count or word cards to make sentences should be promoted as valuable tools rather than shortcuts.
- Teaching sight recognition of common words may be helpful in the early stages of literacy development to allow for some success and confidence in their reading ability when sounding out strategies are hampered by limited working memory skills. Phonetic sound cards are also helpful for children.
- A very useful guide to working memory difficulties can be found at <www.york.ac.uk/res/wml/Classroom%20guide.pdf>

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 academic performance. Young children are particularly vulnerable because they have not had time to develop skills to compensate for areas of difficulty. Missing part of the early years of learning due to illness or because of hospital appointments presents further hurdles as children can often miss learning the 'building blocks' necessary for academic progress in later primary school.

The result can be gaps in knowledge that can leave a child feeling lost and frustrated when they are expected to know information they have not seen before. So if we use the example of a race, some children commencing or returning to school following treatment will start the race behind their peers and will also be slower at getting around the track.

The academic focus of the first years of schooling is literacy development and number recognition. You may find that this does not come naturally to your child and that they struggle to keep up with their peers. Some teachers may interpret this as representing specific learning difficulties in literacy or numeracy; however, it is more likely that your child has difficulty with the learning processes described above and that difficulties become evident in whatever skills are coming 'on line' at their age. Therefore, literacy and numeracy remediation programs may have limited success if the information is not presented with the strategies described previously in mind. Having teachers, tutors and family members all use the same strategies to target your child's particular weaknesses will further increase the possibility of success and progress.

The first step to helping your child reach their academic goals is to understand how they learn best. With this information in hand you will be able to meet with their teachers and principal to map out an Individual Learning Plan (ILP). This should include a set of strategies to compensate for your child's unique set of strengths and weaknesses. 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.

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

1. Become familiar with your child's teachers and principal or vice principal. Ask for regular Program Support Group (PSG) meetings to keep close track of your child's progress and ensure that consistent strategies are being used at home and school. Meeting once a term is recommended to establish and monitor a learning program for your child. If your child is receiving additional support through a tutor or integration aide then it is a good idea for them to also attend these meetings.
2. Structure, routine and providing step-by-step instructions are important for all types of challenges that students face. Have instructions placed on the board, picture charts 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 aides will help most children.
4. 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.
5. Your child may be eligible for tutoring through the Ronald McDonald Learning Program. A referral can be made by a parent, teacher, doctor or other staff member via the website <https://learningprogram.rmhc.org.au/index.php>

Children who experience mental fatigue may seem irritable, restless or teary at times, with their behaviour mistaken for laziness or a lack of motivation.

Other factors affecting academic performance

Additional factors may be contributing to your child's academic and social success in the school environment.

Fatigue

Fatigue is another important factor to consider when looking at your child's academic progress and social success. 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 (such as slow handwriting or an unusual gait). However, your child may also be experiencing mental fatigue which is often harder to identify. Mental fatigue can result from the extra effort required for a child with cognitive late effects to learn new skills. It affects their ability to focus and sustain attention and to process and recall information. Children who experience mental fatigue may seem irritable, restless or teary at times, with their behaviour mistaken for laziness or a lack of motivation.

Children who suffer from physical or mental fatigue are usually exhausted by the end of the school day. They find it particularly difficult to focus on after-school activities and can often fall asleep on the couch after returning home from school. Some simple strategies to reduce the amount of activity required by your child will assist with energy levels. For example:

- Physical education classes may require modification, with a reduction in high-intensity sports and allocation to other duties when possible (such as refereeing sports games, scoring or rest periods).
- Make sure teachers know what to look for; for example, a child looking vacant, getting restless, yawning or 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.

- Short breaks throughout the day are 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 minutes to keep 'zoning out' to a minimum.
- Keep after-school activities to a minimum and encourage early bedtimes to ensure your child is fresh and active in the morning.
- Engaging in low-output physical activities between tasks can help children refocus. Allow your child or student to have a stretch or to go outside for a drink of water or send them on a quick 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.
- Power naps after school for 20–30 minutes can help 'reboot' a child for the rest of the day.

Emotion regulation

The emotional responses of children who have been treated for a major illness can be very different depending on their age, treatment regimen and experiences. Do not assume your child identifies as a cancer survivor and wants everyone to know about this. Children treated at a very young age can be unaware of how their early experiences are different from others and therefore do not experience feelings of loss or missed opportunity that often accompany the illness experience for older children and adults. It may even surprise some parents to see how quickly their child immerses themselves in 'regular kid' activities and behaviours once they are well. It is important to recognise that your experience of your child's illness as a parent has likely been very different from theirs and that they may not identify as a patient, victim or conqueror of cancer.

It is important to try to find a middle ground when 'finding a place' for your child's illness experience in their life, especially when they are very young. Try to not let it become a 'secret' or something to be avoided talking about. Young children are generally not worried about words such as 'cancer' or 'leukaemia', especially if you can talk with them about it in a calm way. However, you may also find that as they grow and enjoy their busy lives their illness is not a topic that needs to be discussed often. Mentioning it in the right context or sometimes looking back on photos of that time can be ways of 'checking in' with your child without making it a big deal. In this way you can make their illness experience a part of your family story but not the whole story!

Sometimes as children's cognitive skills develop, they may surprise you by asking questions about their cancer or treatment. Generally speaking, providing an open and honest style of communication will enable your child to ask you questions about their illness or raise concerns that they may have as they get older. If they do ask questions, try to respond honestly and with age-appropriate language. If talking about their cancer your conversation can also include positive messages such as reminding them that they are well and healthy now.

Your child's behaviour is the best guide for how you should address their illness experience and planning for the future. While many children will adjust well to life following treatment, some struggle to make this transition. As young children find it difficult to identify and label emotions, these difficulties are often expressed as acting-out behaviour or withdrawal. Teaching your child to recognise how they feel and what makes them feel better is an important process.

For young children, drawing pictures can be a powerful medium for expressing their emotions and understanding what is contributing to their behaviour. Naming their emotions (and your own emotions) can be very helpful in helping them to understand and express their feelings. Kimochi dolls (available at <www.kimochis.com.au>) can also be a useful toy to help you discuss and identify emotions with young children. The dolls are cute soft toys that come with a set of 'feelings' (little stars, clouds, etc.) that the child places in the pocket of the doll to indicate how they are feeling today. They are a good way to start a discussion with your child about what feelings are and how they are part of us.

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.precisionacademics.com.au/Level%201%20Sample%20Activities.pdf
- www.melbournecitymission.org.au/services/children/early-years-services

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:

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

Reward charts

Reward charts work really well to promote positive behaviours and confidence in your child. They encourage children to believe in themselves. There are many different ways to make a reward chart but the key features are to make it look great, keep it simple (only one or two behaviours targeted each week), make sure the reward is clear, let your child mark the chart themselves when they show the behaviour and keep it in a highly visible area where the whole family can see and comment on it.

Sarah's Reward Chart

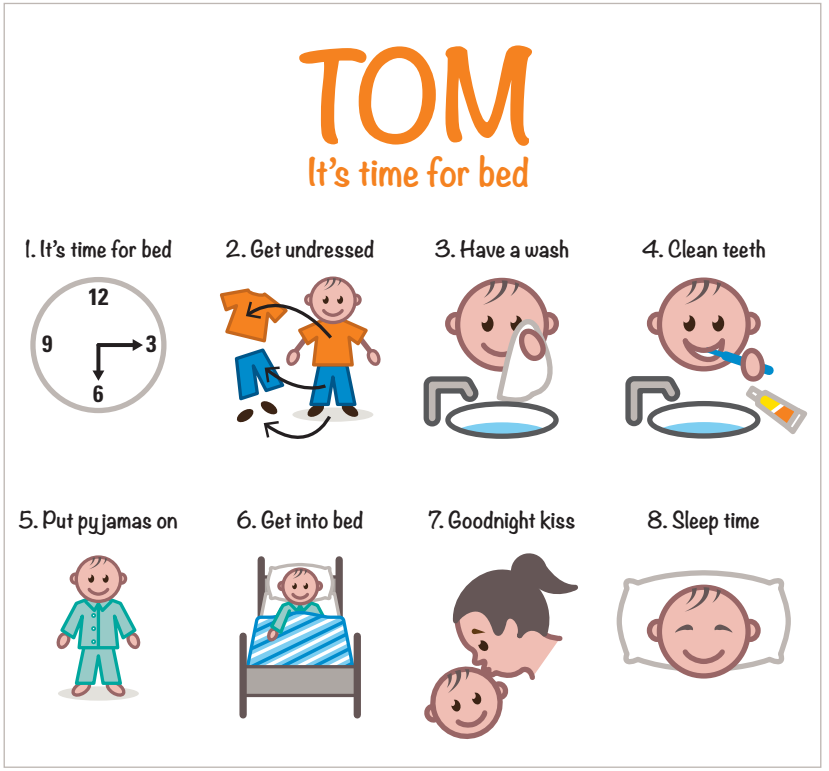
Task	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
7.15am Get dressed	☺	☺	☺				
7.30am Brush teeth	♥		♥	♥			

My goal is 10 stickers

My reward is _____

Routine charts

Helping your child to establish routines encourages independence, minimises conflict and saves time. The best routine charts use photos of the child (or their alter ego, like Spider-Man or Peppa Pig) to show the activities that need to be completed. Here's what a 'getting ready for bed' chart might look like. Remember to make the chart large enough to see from a distance, look cool, uncluttered and inviting.



Useful contacts

Long Term Follow-Up Program

Phone: (03) 9345 9152

Email: ltf.program@rch.org.au

Children treated at a very young age can be unaware of how their early experiences are different from others and therefore do not experience feelings of loss or missed opportunity that often accompany the illness experience for older children and adults.

Useful websites

Paediatric Integrated Cancer Service (PICS)
www.pics.org.au

Australian Cancer Survivorship Centre (Peter MacCallum)
www.petermac.org/about-us/australian-cancer-survivorship-centre

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

Playgroup Victoria
www.playgroup.org.au

Victorian Department of Education and Training
www.education.vic.gov.au

American Speech Language Hearing Association
www.asha.org/public

PBS Parents
www.pbs.org/parents

dysTalk – information for parents on specific learning difficulties
www.dystalk.com

Getting ready to read – information for parents and teachers for children with learning disabilities
www.getreadytoread.com

Preschool activity box
www.preschoolactivitybox.com

Skill-builders Paediatric Occupational Therapy
www.skillbuildersonline.com

Kidspot Australia
www.kidspot.com.au

GymbaROO Child Development
www.gymbaroo.com.au

The Centre for Working Memory and Learning, University of York
www.york.ac.uk/res/wml

Ronald McDonald Learning Program
www.learningprogram.rmhc.org.au

Kimochis – toys with feelings inside
www.kimochis.com.au

Precision Academics – resources for students who have special learning needs
www.precisionacademics.com.au

Raising Children Network
www.raisingchildren.net.au

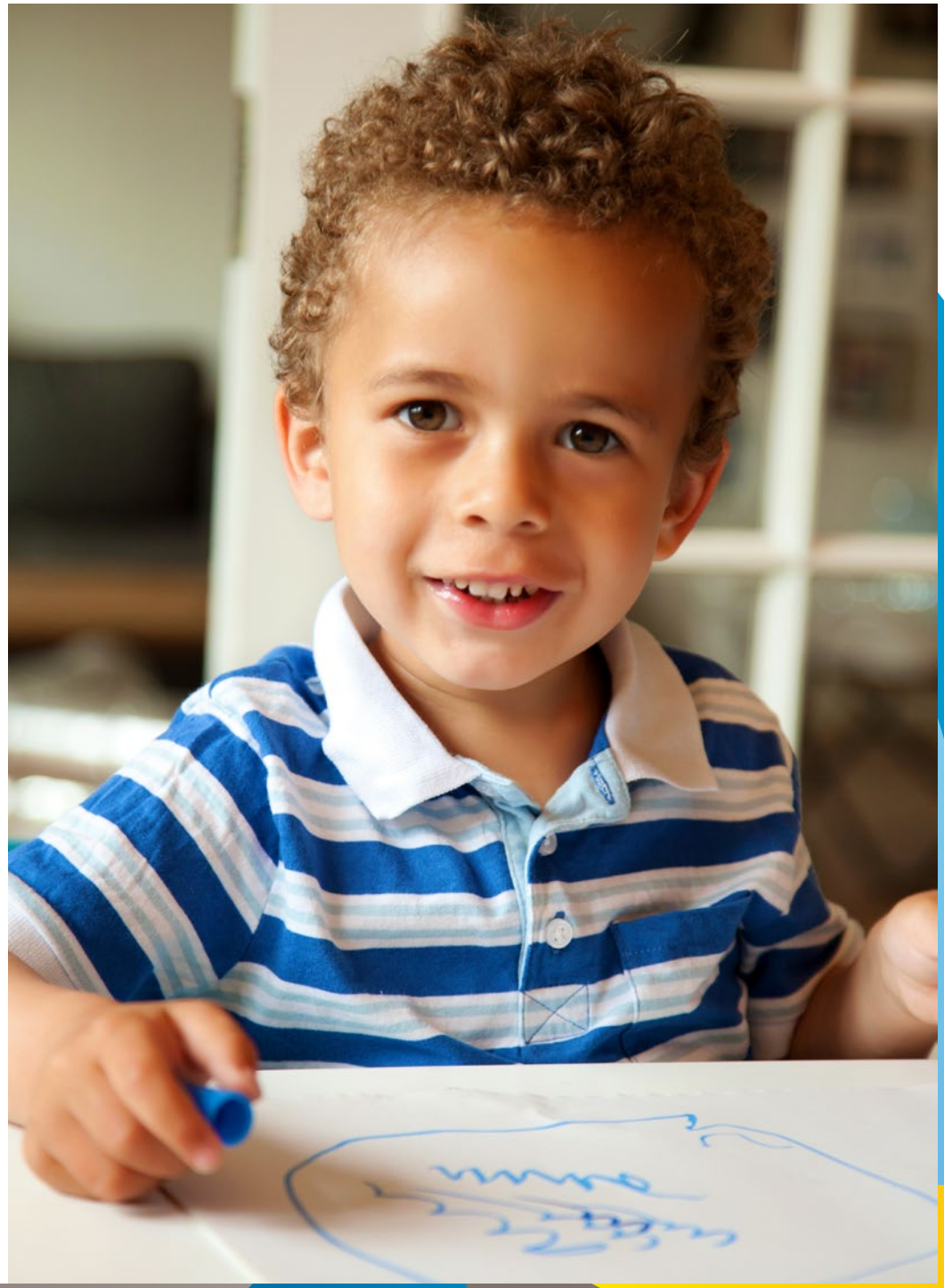
Melbourne City Mission
www.melbournecitymission.org.au

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
Primary to early secondary school

Learning curve: education and socialisation after childhood cancer
An information booklet for adolescents, parents and teachers
Senior secondary school



Paediatric Integrated Cancer Service

A statewide cancer service for children

Paediatric Integrated Cancer Service
Administrative Host:
The Royal Children's Hospital
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50 Flemington Road, Parkville, Victoria 3052
Telephone +61 3 9345 4433
Fax +61 3 9345 9163
Email pics.admin@rch.org.au

ERC 150537