The ROYAL MARSDEN
NHS Foundation Trust

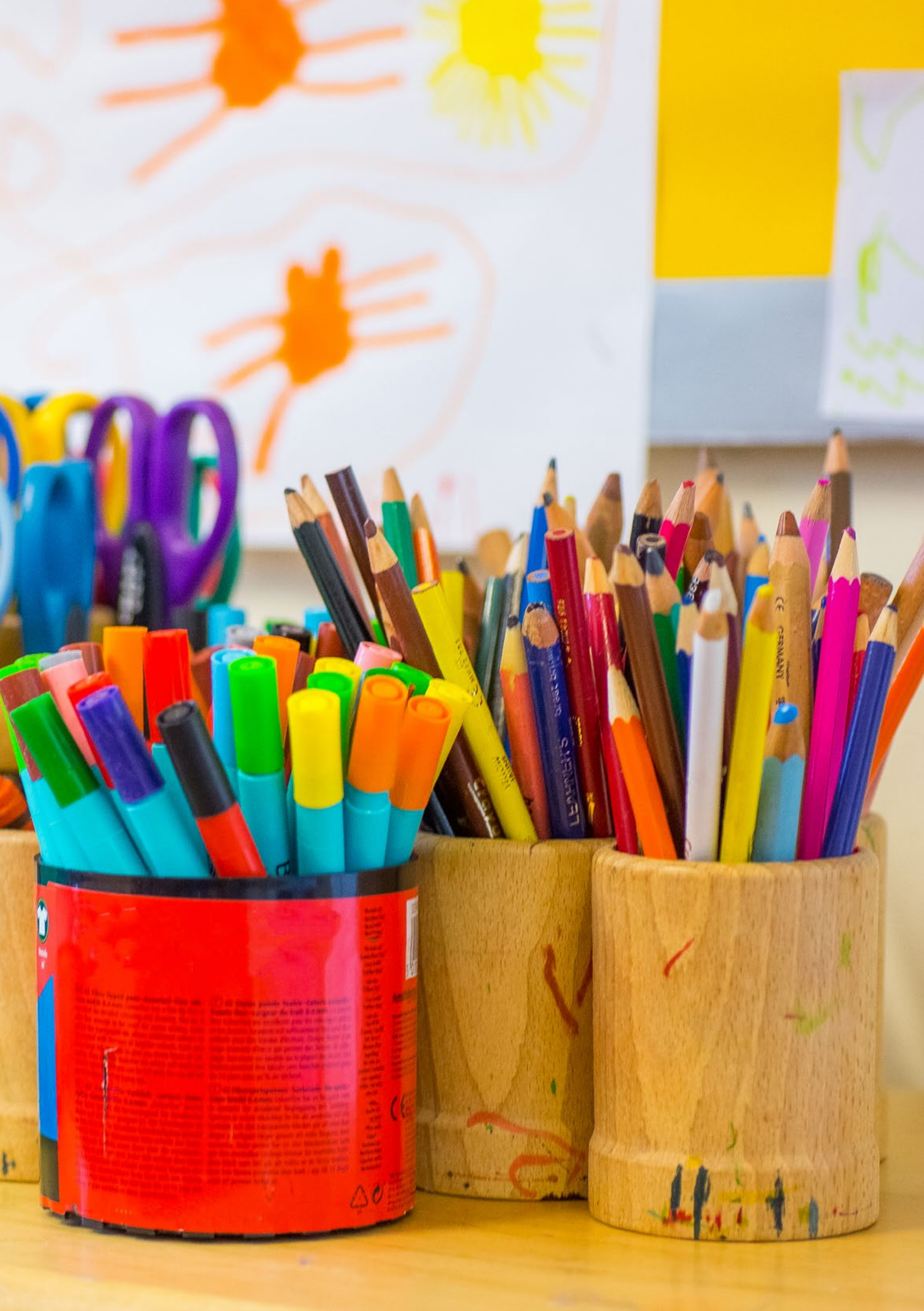
Supporting children with cancer in school

Maximising learning, enabling participation and promoting wellbeing through positive school experiences

Guidance for primary school teachers from an Occupational Therapy perspective

NHS

Contents



Introduction

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Children with cancer may have difficulties engaging in some tasks and activities due to the effects of cancer and cancer treatment on the body and brain. Difficulties may also be due to prolonged periods in hospital when daily life and education are disrupted. These difficulties can have a big impact on their engagement and experience in school.

School is central to a child's life, their wellbeing and sense of purpose, and their intrinsic drive to learn and play. As the adults responsible for a child's education, you can enable these children to remain children. You can give them choice, help them to engage, enable them to learn, keep their friends, feel a valued member of their school and enjoy the experience of education.

Your guide to using the information pack

The difficulties children can experience when they return to school can be greatly reduced by altering the process or the demands of an activity, or adapting the environment where the activity takes place. This booklet provides information and ideas to help teachers make changes to a child's activities and their environment.

Just like you would adapt the environment and delivery of lessons for a child hard of hearing, you might need to do the same for a child with cancer. Think creatively when trying to integrate the advice and strategies. Be sure to ask the child if something has helped or not – they are often the best judge.

The OT Plan website is great for ideas of fun activities to develop coordination and fine motor skills. You could even get your computer whizz kids to choose some for themselves via **www.otplan.com**

If you have any further questions after reading this booklet, please contact the Occupational Therapy department on 020 8661 3090.

Cancer and cancer treatment

The main types of cancer in children are blood cancers (ie leukaemia) and brain tumours.

The most common treatments used to treat cancer are chemotherapy (drug treatment) and radiotherapy (beams of radiation projected into an area of the body). There are a number of common side effects experienced during and after receiving chemotherapy and radiotherapy. These are the common side effects and the problems they may cause on ability in school.

Side effects on the body

Nausea and vomiting

Hair loss

Skin blemishing

Blistering of lips and mouth

Loss of feeling, tingling, pins and needles in extremities

Loss of muscle strength and control

Fatigue and tiredness

Effects on ability

Feeling unwell

Feeling self conscious about appearance

Speech, eating and drinking difficulties

Discomfort, poor sensation in hands, difficulty manipulating objects

Difficulty walking, sitting/standing and coordinating movement

Effects on participation

Not wanting to participate

Becoming shy/withdrawn

Difficulty communicating with peers

Poor participation due to discomfort and confidence

Decreased independence in daily activities

Difficulty moving around and joining in active activities

Difficulty coping with demands of the school day

Effects of brain tumours

The effects of brain tumours will be different in every child but these are some of the common problems.

The main side effects of cancer are caused from treatment described on the previous page. The child's parents will be able to tell you about their child's specific difficulties and any precautions that need to be taken. Children with brain tumours typically have more complex difficulties and the effects can differ from those previously described. These are the common difficulties a child with a brain tumour can have.

See page 14–16 for strategies and activities to minimise the impact of these difficulties on ability and participation.

Effects on the body

Alteration in how the brain processes information

Loss of muscle strength and control (changes in tone and coordination) often one sided

Changes to processing sensations

Effects on ability

Poor attention and concentration

Changes in cognition

Difficulty with two handed, fine and gross motor activities

Decreased balance and postural control

Effects on participation

Difficulty coping in unfamiliar, busy or changing environments

Difficulty moving around and joining in movement based activities

Extreme/unusual responses to sensations and pain

Returning to school

Introducing a child with cancer back to school can be daunting for everyone involved. Creating a plan with the parents and child will help to ease everyone's worries and ensure things happen as the parent and child wish.

Preparing the child's peers

Some children may be happy to be asked directly by other children about their illness whereas other children may find this upsetting, in which case it may be best to encourage peers to ask questions away from the child. Agree with the parents and child what will work best for the child to prevent unnecessary upset, anxiety or confrontation.

See page 24–25 for psychosocial, body image and physical appearance factors to consider when preparing the child's peers.

Establish what the child's main difficulties are

Establish what the parents' and child's priorities are

Agree what other children will be told about the child's illness

How will the school environment impact their difficulties?

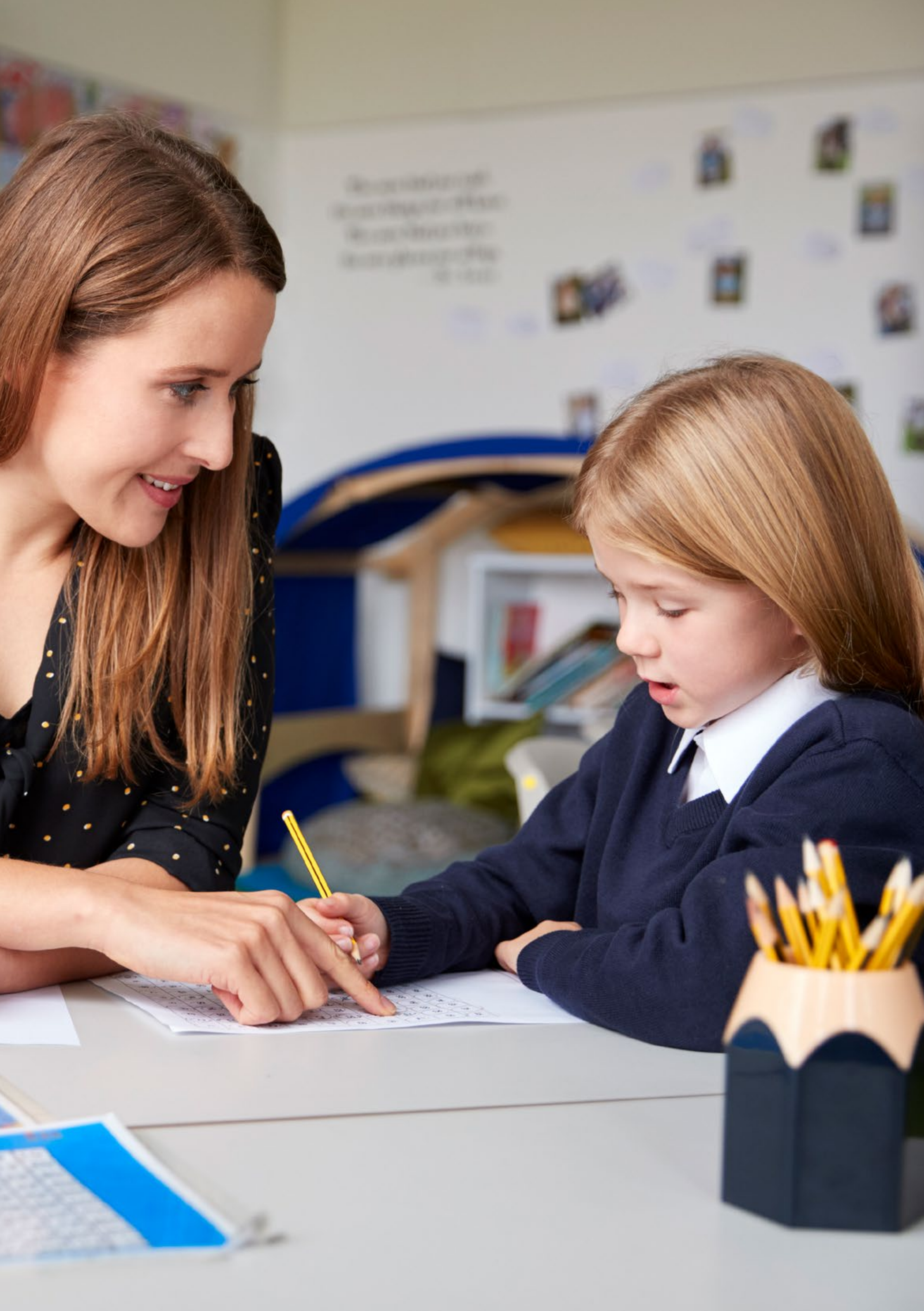
How can school activities and the environment be tailored to minimise their difficulties?

Do the parents want to set educational goals/targets?

Do parents wish the child's engagement and enjoyment to be the focus?

Agree how questions from the child's peers will be dealt with

Discuss telling peers if the child has obvious changes to physical appearance or ability ie hair loss, speech or movement difficulty



How to maximise ability and enable participation

Bilateral coordination skills

This section gives ideas of activities and strategies to enable a child to function to their best ability at school.

Children may have difficulties using both hands together and coordinating movement on both sides of the body.

Make things easier

Give the child the opportunity to practice activities they find difficult in a quiet distraction-free environment

Remove unpredictable things the child has to respond to (ie tell the child where and when you are throwing a ball to them)

Use larger, slower-moving and easier to hold objects

Give visual demonstration of tasks

Give lots of verbal prompting during activities

Activities to develop skill

Consider using the whole whiteboard to draw or large sheets of paper on the floor

Activities using both sides of the body together; two handed catching and throwing, riding a bike

Washing up, tidying away, moving tables

Animal walks

Hopscotch, jumping patterns

‘Simon says’ – instructing moving body parts in a specific way

Fine motor skills

Children may have difficulty holding pens and pencils, doing fastenings on clothes, picking up and moving small objects in the hands.

Make things easier

Write on a writing slope/type on a laptop

Use loop or wide handle scissors

Use triangular pens and pencils or grips

Use software packages that enable dictation

Work in pairs

Use worksheets to reduce writing demands

Allow regular rests during writing/cutting/craft activities

Try hand massage or gentle movement of the hands in warm water to relax hands and relieve pain

Activities to develop skill

Games with small parts (marbles, cards, Operation)

Make animals, shapes, numbers and letters from Play-Doh

Pulling, tearing, stretching and pressing activities using the hands and fingers

Building with Lego, K'NEX or blocks

Finger painting

Practice fluency patterns to improve pencil control

Craft/threading activities (beads etc)

Make up games to play with pegs, tongs and tweezers

Gross motor skills and balance

Children may have difficulties in PE and games, appear ‘clumsy’, have poor sitting posture and find playground equipment challenging.

Make things easier

Use large compressible balls for catching and large bats for hitting

Break activities down into smaller parts and give clear single step instructions

Sit in a chair of a height so that feet are firmly on the floor and back is supported

Regular rests during ‘active’ activities/play Wii sport games

Sit down to do activities where possible

Allow shoes to be kept on during indoor PE – wear trainers not plimsoles

Activities to develop skill

Running, jumping, skipping, walking backwards/sideways

Sports – throw and catch, bat and ball games

Climb on and around apparatus

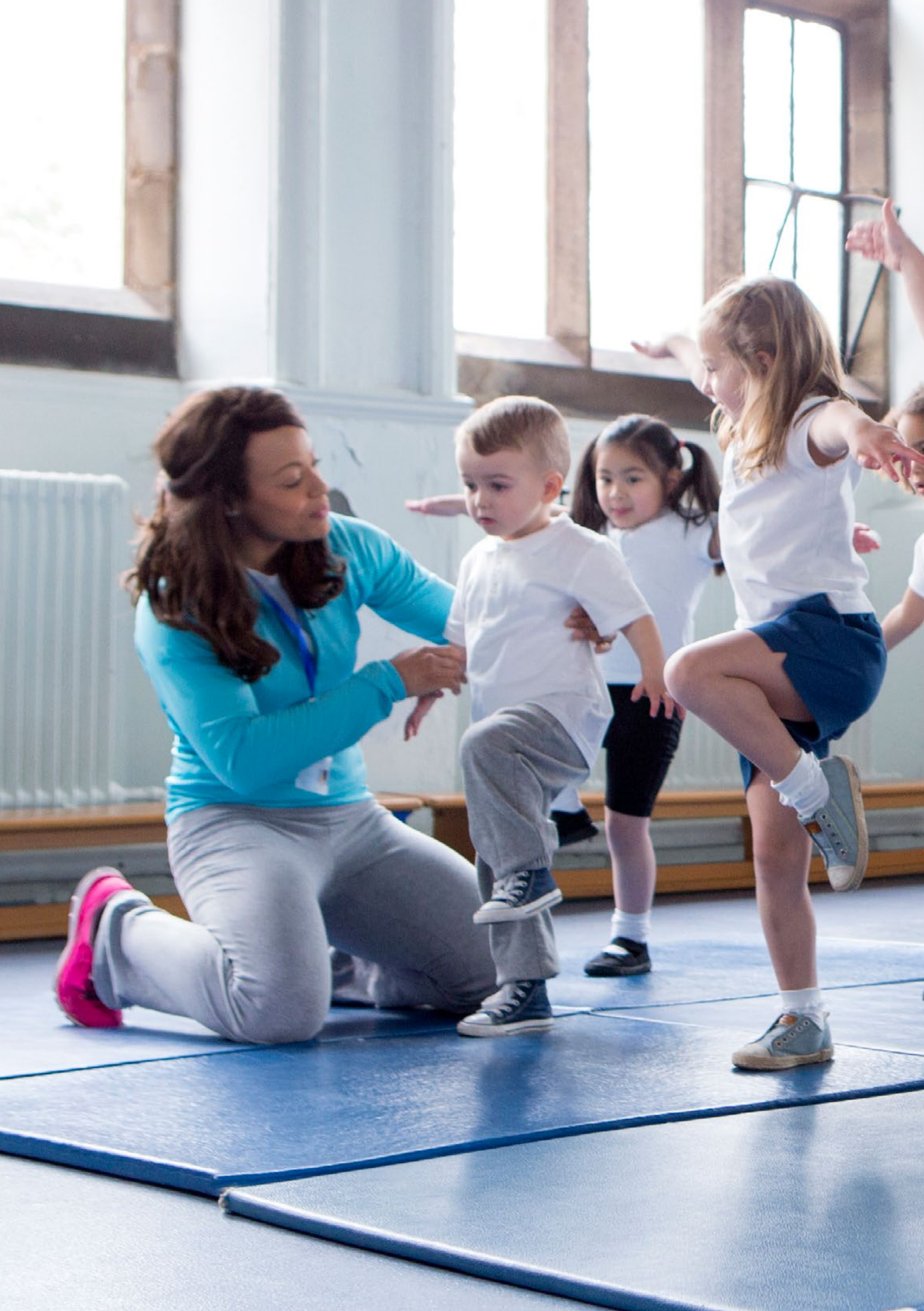
Make obstacle courses and change them regularly

‘Simon says’– instruct moving body parts in a specific way

Table top activities in different positions – on an easel or lying on tummy

Walking on balance beams and balance games

Twister



Visual perceptual skills

Children may have difficulties with reading and copying things (letters and shapes) and difficulty with puzzles.

Make things easier

Use sky, grass or wider lines for writing

Remove unnecessary background shapes and images from worksheets, books and whiteboards

Use distinctive, clear text and avoid changing font style and size

Give visual reinforcement of instructions in these activities

Break activities down into small steps

Activities to develop skill

Practise doing puzzles, building with blocks, bricks, Lego, K'NEX

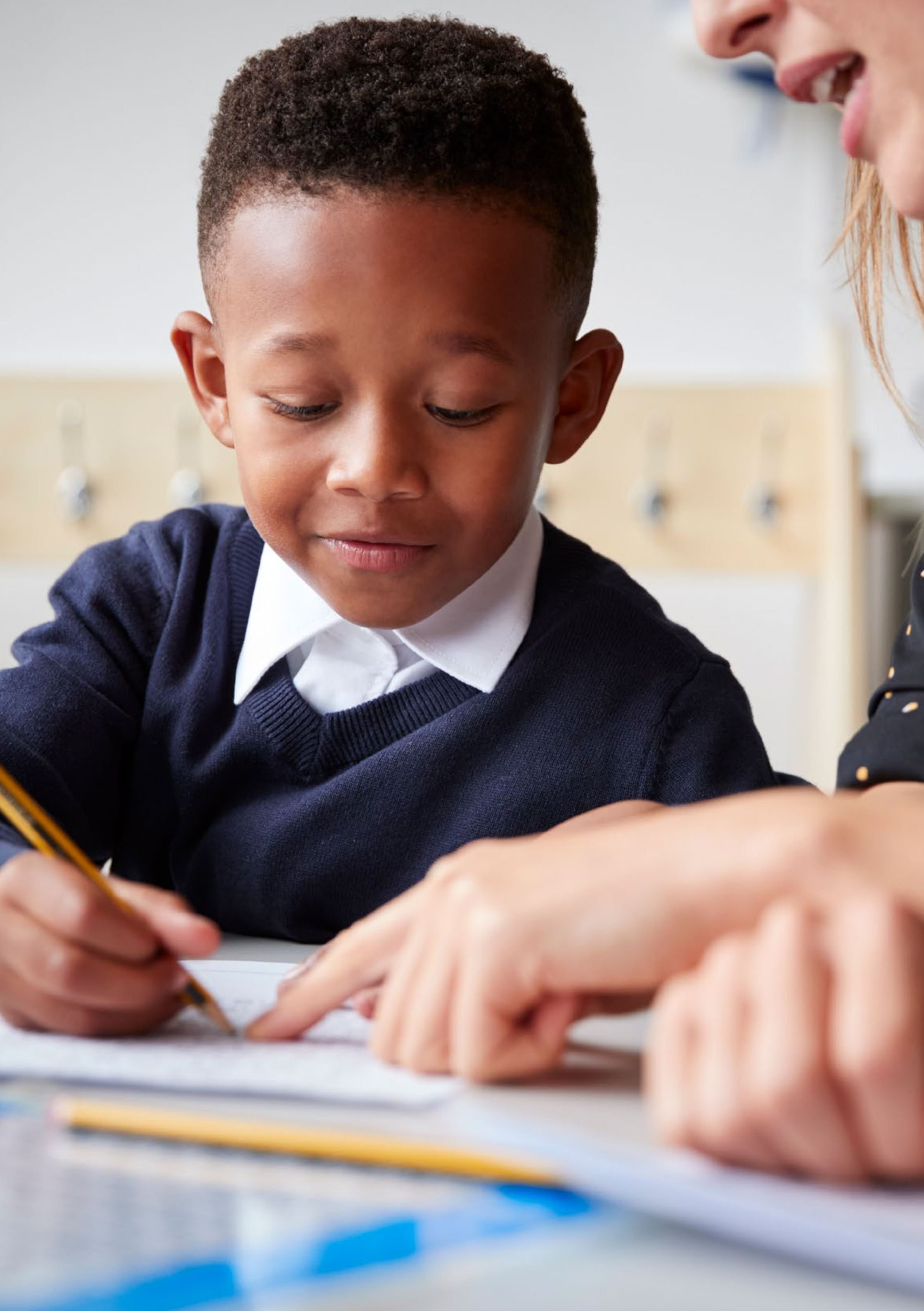
Copy patterns, pictures and shapes

'Where's Wally', word searches, spot the difference, dot to dot and colouring in

Practise pre-writing skills

Play board games

Play card games such as snap



Memory

Children may have difficulties with their memory. They may appear disorganised, forgetful or have difficulty remembering recent events and learning.

Make things easier

Teaching strategies to aid remembering: visualising the object or event, associating something with a memorable event or object, repeating to self, writing lists (add colour or pictures as reinforcement)

Use cue cards for visual reminders of what activity to do next or to remind the child of the next stage of the task

Use visual timetables, schedules and a notebook to write things in

Attention and concentration

Children may have difficulties with their attention and concentration. They may become easily distracted, struggle to focus, fidget and need to be constantly moving.

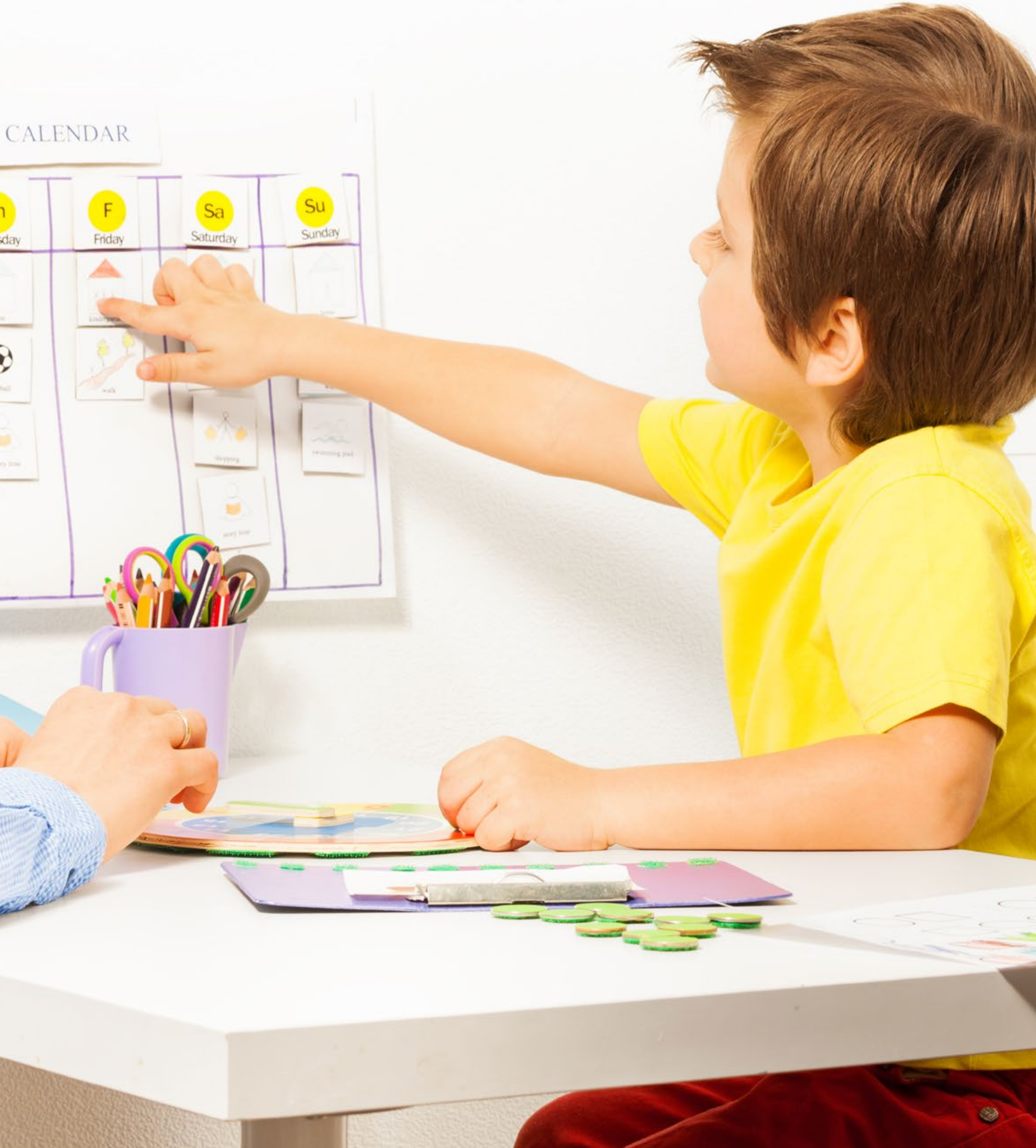
Make things easier

Use cue cards to prompt remaining on task, breaking activities down into component tasks

Give activities a clear beginning and end

Reduce unnecessary distractions – noises and visual things

Keep activities short and allow short movement breaks in between activities


CALENDAR
F
Friday
Sa
Saturday
Su
Sunday
walk

Considering psychosocial factors and participation

Considering psychosocial factors and participation

Children with cancer often experience psychosocial difficulties which can impact upon their participation and development. Some of the psychosocial difficulties that are common are lack of confidence, body image, self esteem, motivation, anxiety, avoidance behaviours, withdrawal, depression and developmental regression.

Most children will have changes in their appearance from either the cancer or treatment side effects. Changes in appearance may lead to body image concerns. Preparing peers for these changes will help to reduce unwanted attention when the child returns. Consider showing peers images of children with the same appearance changes as their classmate has.

These are common appearance changes – skin blemishing and colour change, bruising, hair loss, difficulty managing mouth secretions, tremor (usually in hands), nasogastric tube, and medicine port in chest (portacath).

Strategies to promote inclusion and to reduce the impact of these factors on participation and development:

- **Nurture groups:** incorporate discussions of body image – for example ask children to identify things they like and don't like about themselves, and to identify something good about other children in the group. This could be alongside other Personal, Social and Health Education (PSHE) topics

  If the child wishes to share their experiences, facilitate discussion in small trusting groups. This can help other children to accept and appreciate how the child may have changed
- **Buddy system:** this can help a child with low confidence and self-esteem to develop confidence and promote their social participation and psychosocial development
- **Clothing:** allow the wearing of head wear and clothing to cover skin and medicine ports and privacy when changing for PE.

Fatigue and tiredness

Fatigue and tiredness

Children may have difficulties with fatigue and tiredness. They may always be tired or easily tired, and may have poor concentration and memory.

- **Time out card** – this enables the child to easily ask to leave an activity when things get too much and can help prevent tears or angry outbursts. This could be a coloured card they are able to turn upside down on their desk to inform the teachers if they have difficulty or are unable to verbalise their emotions.
- **Quiet corner or chill out zone** – a place where the child can rest for short periods throughout the day; it could be in the corner of the classroom or the library
- **Pacing** – this is how you can pace (spread) energy expenditure efficiently throughout the school day which helps to conserve energy. Try to spread more energetic activities across the school day with periods of rest in between. A child may have more energy at the beginning or end of the day, so find this out and factor that into their activity timetable
- **Saving energy** – decide what changes to the child's school day can be made that will save energy – sit on a chair instead of the floor, have a buddy to collect things during lessons, encourage more sedentary play at break-time, not having to walk round school to different classes. Use pacing strategies in PE lessons and have the child help coach or umpire during lower periods of rest.

Non-curative cancer

Non-curative cancer

When a child's cancer cannot be cured their condition may be said to be palliative.

The impact of this will greatly depend on:

- the type of cancer
- the treatment plan
- the child's and family's preferences.

End of life is not necessarily imminent and maintaining participation in school activities may be important to the child and their family.

- **Palliative care:** a child must be physically well enough to attend school. Medical and nursing staff will support the school to manage any medical needs the child may require whilst in attendance
- **Expectations:** you need to be as flexible as you can. Agreement of an education plan with the family will help to meet needs of the child. The emphasis in these cases should generally be on enabling the child to participate in the activities they wish to. The way in which the child participates can be tailored to their needs – this may be more passive participation
- **Hospice involvement:** when a child's cancer is non-curative they are often linked into a children's hospice. This is not only for end of life care but also to promote participation for the child and their family in the time leading up to end of life. Day trips, respite and support for the family are all available, so some time away from school may be necessary
- **Functional changes:** a child may present with some functional changes which impact their ability to engage in school in the way they did before. Medical and therapy staff may be able to discuss with parents or directly with the school, to plan how best to support them in the school environment.

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This booklet is evidence-based where appropriate and where evidence is available.

Details of the references used in writing this booklet are available on request from:
The Royal Marsden Help Centre

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The information in this booklet is correct at the time of going to print.

Should you require information in an alternative format, please contact The Royal Marsden Help Centre.

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The patient information service is generously supported by The Royal Marsden Cancer Charity.

royalmarsden.org

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The Royal Marsden publishes a number of booklets and leaflets about cancer care. Here is a list of information available to you.

Diagnosis

- A beginner's guide to the BRCA1 and BRCA2 genes
- CT scan
- MRI scan
- What is an ultrasound scan?
- A beginner's guide to Lynch syndrome

Treatment

- Central venous access devices
- Chemotherapy
- Clinical trials
- Radiotherapy
- Radionuclide therapy
- Your operation and anaesthetic

Supportive care

- Eating well when you have cancer
- Reducing the risk of healthcare associated infection
- Support at home
- Your guide to support, practical help and therapies

Your hospital experience

- Help Centre
- How to raise a concern or make a complaint
- Your health information, your confidentiality

Please visit **www.royalmarsden.nhs.uk/patientinfo** where many patient information booklets are available to download.

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