



# CANCER AT SCHOOL

# SUPPORT GUIDE FOR TEACHERS



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### Pediatric cancer: a few figures

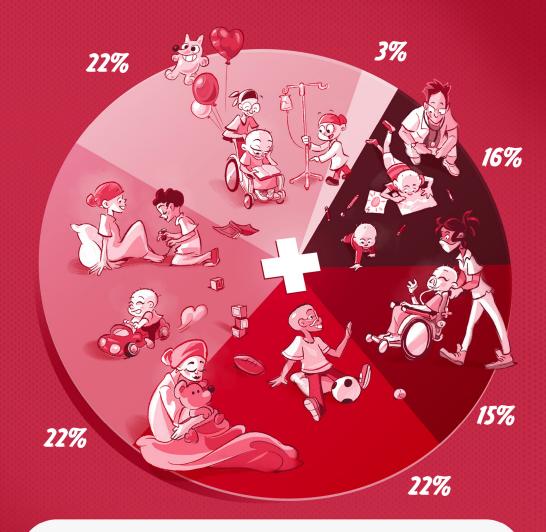
The diagnosis of pediatric cancer is a reality
that affects some 400,000 children between 0 and
19 years of age each year worldwide. Cancer remains
one of the leading causes of death in children, with
approximately 100,000 deaths from the disease each year.
The most common types of childhood cancer include leukemia,
brain tumors, lymphoma and neuroblastoma.

It is important to note that pediatric cancer differs from adult cancer in terms of types, cure rates and specific treatment needs.

Despite many advances in research and treatment, children with cancer and their families face significant emotional, physical, educational

and financial challenges.

## Approximately 350 children under the age of 19 are affected by cancer every year in Switzerland\*.



- 10 survive without late effects.
- 77 will survive beyond the age of 30 with minor late effects.
- 77 will survive beyond the age of 30 with moderate late effects.
- 77 will survive beyond the age of 30 with significant late effects.
- 53 will die within 6 to 30 years of diagnosis.
- **56** will die within 5 years of diagnosis.

<sup>\*</sup> Figures adapted from Cancer in Switzerland, 2021 report, published by the Swiss Federal Office of Statistics.

### The most common pediatric cancer

LEUKEMIAS

BRAIN TUMORS LYMPHOMAS

**NEUROBLASTOMAS** 

Early detection and appropriate treatment can improve the chances of recovery and quality of life for most affected children, but the late effects of disease and treatment can sometimes be significant and can have a major impact on a child's quality of life.

### The most common physical impacts

#### **Gross motor skills**

Pediatric cancer treatments, such as surgery, chemotherapy and radiotherapy, can have harmful effects on the child's gross motor skills.



Possible repercussions of these aggressive treatments (non-exhaustive list):



- muscle weakness
- extreme fatigue
- coordination difficulties, affecting a child's ability to move around and perform physical activities.
- motor skill developmental problems
- temporary or permanent paralysis
- ENT disorders, such as problems swallowing
- delays in the acquisition of motor skills in children, often requiring rehabilitation and long-term follow-up to minimize the impact on gross motor skills.

#### Fine motor skills

Fine motor skills may also be impaired:

- tremors
- reduced coordination of fine hand and finger movements
- difficulties with activities requiring precision and dexterity.

The toxicity of the treatments can affect a child's ability to write, draw, handle small objects and perform intricate tasks, which may result in the need for specialized care to boost the development and rehabilitation of fine motor skills.

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### Visual perception

Children with cancer may suffer from various visual perception disorders due to the side effects of treatment:

blurred vision



light sensitivity

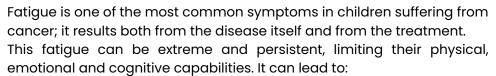


altered color perception

difficulty focusing or tracking moving

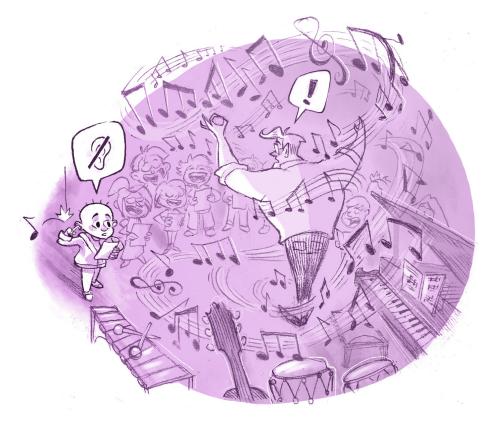
These problems can have a significant impact on a child's quality of life, affecting their ability to read, play and interact with their environment. It is essential that these disorders be diagnosed and treated early to help the child adapt.

#### Fatigue



- reduced appetite
- irritability
- sleep disorders
- difficulty concentrating

It is essential to effectively manage fatigue in children with cancer by adapting activities, encouraging rest and offering psychological support to help them cope with this chronic fatigue.



## Auditory perception 🦠



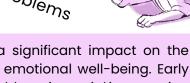
Children suffering from cancer may also experience perception deafness due to the effects of treatment on the auditory system:

partial or total hearing loss

hypersensitivity to loud noises tinnitus

difficulty distinguishing sounds or or following a conversation





These hearing problems can have a significant impact on the child's communication, learning and emotional well-being. Early detection and treatment of hearing problems is crucial in assessing treatment options.

## Headaches 🔆

Headaches are sometimes observed in children with cancer and are often caused by the disease itself or the side effects of treatment.

These headaches can be intense, persistent and sometimes associated with other symptoms such as nausea, vomiting or visual disturbances. Headaches can affect the child's quality of life, disrupting their sleep, appetite and ability to participate in daily activities.



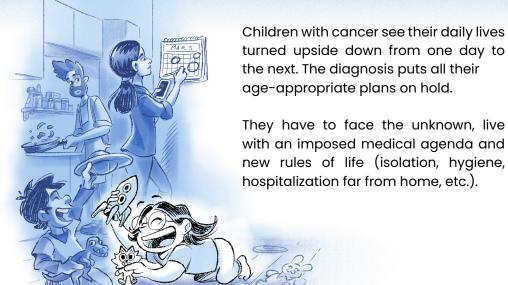
## Epilepsy 🥰



Seizures can occur in children with cancer due to a variety of factors, such as the presence of brain tumors, the effects of treatment or diseaserelated changes in brain function. These seizures may manifest as convulsive movements, altered consciousness, involuntary movements or abnormal sensations.

Epileptic seizures can be frightening for the child and their family, and require appropriate medical management to control symptoms, prevent complications and ensure the child's safety. Regular follow-ups by a specialized medical team are essential.

## The most common psychosocial and emotional impacts



They have to face the unknown, live with an imposed medical agenda and new rules of life (isolation, hygiene, hospitalization far from home, etc.).

Every child will experience illness differently, but there will always be a psycho-social and emotional impact. The body will undergo transformations, treatments will affect mood and the way others see them may change. The child's reaction will depend on their age, personality, diagnosis, prognosis and duration of treatment.



Maintaining regular contact with the child and their family during their absence is essential for a smooth return to school.

## Acceptance of the disease

Each child puts in place more or less functional defense mechanisms that are specific to them and that enable them to cope with the disease-generated anxieties.

They may have reactions of sadness, fear, hope and silence. They may also have strange attitudes. It's their way of dealing with their immense anxiety. They could also comply with adult expectations, over-adapt or become an active partner in their own treatment. They will often turn to an adult or friend who will become their confidant.

## **Self-image**

The child will most likely lose their hair, eyelashes and eyebrows. They may gain or lose weight and end up with a nasogastric tube. They may have visible scars and discover that their body has been weakened by the disease and no longer responds as it used to. They may have to ask their parents for help with everyday tasks and may have to give up sporting activities.

This is an exceedingly difficult period for them, as they see that they are physically changing, which may lead to suffering, incomprehension, and a sense of injustice. They don't know how to accept this new image of themselves. Some teenagers find this period of intense public scrutiny particularly difficult as they are already dealing with the physical changes brought on by puberty.

#### **Mood - Mental state**

The announcement of an oncological diagnosis is a shocking and potentially traumatic experience.

Both the child and the family may experience a state of shock and disorientation, which may last for some time. This can be followed by a variety of reactions, including depression, anxiety, behavioral problems, restlessness, difficulty concentrating or memorizing, and social withdrawal, to name but a few. Some children start to panic, feel nauseous, anxious and irritable even before they arrive at the hospital. Others talk a lot or ask questions to hide their stress. Some treatments can affect a child's mood and behavior. The family may no longer recognize their child who may become agitated or apathetic and may no longer tolerate frustration.

The child may show signs of impatience, anger or indifference and may take refuge in silence and isolate themselves. Their reactions are unpredictable, and they are often the first to be surprised. It's very difficult for them to deal with so many emotions.



#### Social behavior

A child's behavior will vary according to their age. They must first cope with all the changes associated with the disease. They find themselves with a puzzle whose pieces don't fit together like they used to. The length of hospitalization will affect their behavior. They may feel embarrassed, shy and apprehensive about returning to their friends and peers.

They can struggle to find their place with their family and friends, and don't always know how to deal with their friends' questions or concerns. Their absences deprive them of positive experiences with their friends, as they are unable to participate in most outings.

They often prefer small-group relationships. Thanks to cell phones, they stay in touch with their friends, but real face-to-face communication remains difficult. When they are at home, they are keen to socialize, but fatigue and hygiene rules quickly limit their opportunities, provoking incomprehension and a feeling of injustice. They find it difficult to accept this new self-image.





# Most common cognitive impacts

Children with cancer may present a variety of neuro-cognitive disorders due to the effects of the disease and treatments on the developing brain. These disorders can have a significant impact on the child's daily life, school learning, social relationships and overall quality of life. Early recognition and multidisciplinary management of these neuro-cognitive disorders is essential to help children overcome these challenges and maximize their recovery potential.

Cancer-related fatigue can also exacerbate these neuro-cognitive disorders, reducing the energy available for cognitive processes and affecting the child's mental clarity. It can complicate the child's concentration, memorization of information and problem-solving skills, leading to lower academic performances and increased frustration.

Neuro-cognitive disorders can also be influenced by psychological factors such as anxiety, depression, stress and trauma related to the diagnosis and treatment of the disease. These factors can cause additional difficulties by disrupting cognitive processes, altering mood and affecting the child's motivation to engage in cognitively demanding activities. A holistic approach that takes into account both the neurological and psychological aspects of neuro-cognitive disorders is essential for comprehensive care tailored to the individual needs of children with cancer.

## Impact on Schooling

The repercussions of the disease and/or its treatment can last for years after the diagnosis or remission and even throughout their life.



## Repeated absences:

Medical treatments and frequent doctors' appointments can lead to repeated absences from school, which can affect classroom participation and the assimilation of knowledge.



## Physical side effects:

Some cancer treatments, such as chemotherapy, radiotherapy and surgery may cause intense fatigue or physical side effects such as nausea, headaches, body aches, gastrointestinal disorders, which can disrupt the child's ability to concentrate in class and participate actively.



## Cognitive Problems:

Cognitive problems such as memory impairment, information processing difficulties and attention disorders can compromise a child's ability to learn effectively.



## Difficulty concentrating:

The effects of medication, surgery and disease-related stress can cause fluctuating levels of concentration, which can make schoolwork more difficult.



## Academic readiness:

Repeated absences, loss of concentration and learning difficulties can cause a child to fall behind academically, often requiring additional accommodation and support to catch up.



## Anxiety and depression:

Living with cancer can lead to high levels of anxiety and emotional stress in children, which can have a negative impact on their mental health and result in a loss of self-confidence.



## Sleep problems:

Disease-related stress, treatment side effects and changes in routine can interfere with a child's sleep, leading to chronic fatigue and difficulty concentrating in class.





## Impact on Schooling



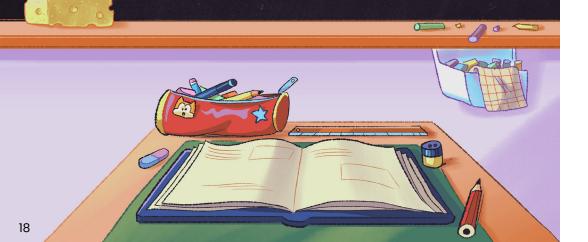
## Diffficulty participating in activities:

Certain types of cancer and certain treatments may limit a child's ability to take part in physical activities (such as gymnastics).

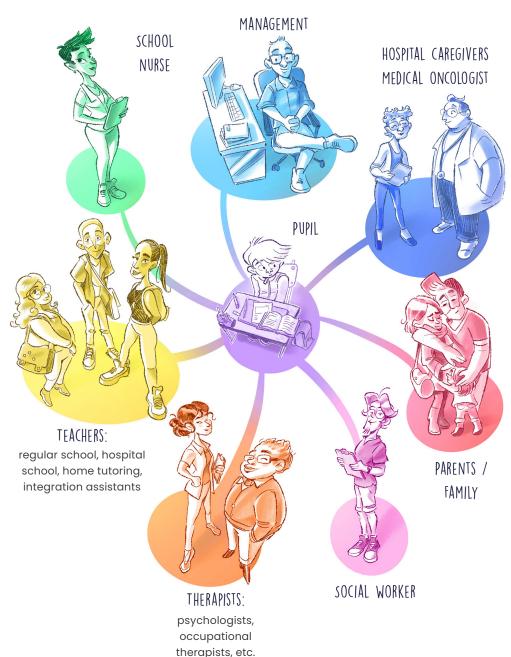


## feeling of isolation:

A child's absence can make returning to school difficult. They may feel isolated, left out. or out of step with their peers. Pupils are sometimes at a loss, wondering how to welcome their classmates.



## Networks of stakeholders around the pupil





# HOSPITAL CAREGIVER / MEDICAL ONCOLOGIST

- Child's medical care
- Clear, precise information on the repercussions of the disease
- Support for family and siblings



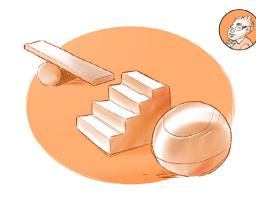
regular school hospital school home tutoring integration assistants

- Monitoring schoolwork
- Link between parents and school
- Link with school at the hospital
- Support for siblings



## SCHOOL MANAGEMENT

- Administrative management (agreements, procedures, etc.)
- Contact person for teachers and parents
- Official communications to the hospital



# THERAPISTS psychologist occupational therapist, etc.

- Emotional and psychological support
- Support for possible ergonomic adaptations
- **Support** for siblings



## SCHOOL NURSE

- Information about the disease
- Links between parents, child, school and hospital from a health perspective (resource person)
- Support for siblings



## SOCIAL WORKER

- Informing schoolmates about cancer
- Good communication between the care team and the school, with the parents' agreement.
   Resource person available for teachers
- Support for siblings



## PARENTS / FAMILY

- Need to be heard/listened to
- Assurance of their child's safety at school and of good academic support
- Regular meetings to review progress
- Support for siblings

To best accommodate the pupil, physical adaptations can be made (in the classroom, in the school, etc.).



Ensure that the school and classroom are easily accessible to the pupil, particularly with regard to ramps, elevators and barrier-free paths.







#### Rest area in the classroom:

Provide a quiet, comfortable rest area where the pupil can relax when needed. This could include a corner with cushions or an armchair away from the noise and bustle.





Rest room or infirmary:





If necessary, use an adult-supervised rest room (e.g. in the infirmary), equipped with comfortable beds or chairs, if the pupil needs to rest or receive medical attention.







#### Lighting and temperature:

Adapt classroom lighting, as light sensitivity can be a problem for some pupils with cancer. Maintain a comfortable temperature.







#### **Physical protection:**

Ensure that a pupil wearing a TIVA
(Totally Implantable Venous Access)
avoids shocks or excessive pressure
on the area where the device is
implanted. In case of doubt, call the
parents, who will discuss the situation
with the referring physician.







#### Ergonomic workplaces:

Provide seating and tables adapted to the pupil's physical needs.



#### Easy access to toilets:

Ensure that pupils always have quick and easy access to the toilet, especially if they have to cope with treatment side effects such as nausea or gastrointestinal problems.







## Personalized emergency evacuation plan:

Develop a personalized emergency evacuation plan for the pupil, taking into account their specific medical needs and designating people responsible for assisting them during an evacuation.



## **Teaching adaptations**

It's important to maintain the child or teenager's status as a pupil and learner.



## 1

#### Flexible school hours:

Offer flexible class attendance options to accommodate treatment, recovery, fatigue and medical appointments.



#### **Access to educational resources:**

Set up remote access to courses and teaching resources (using a tablet or robot, for example) so that pupils can continue to learn. Offer duplicate copies of the manuals (one for home use and one for school or hospital) or online access to them.



#### Pedagogical adaptations:

Adapt the pace and volume of work to take account of the pupil's fluctuating energy and concentration, during treatment, recovery and for as long as necessary. Prioritize quality over quantity.



#### Flexible assessment:

Use alternative assessment methods. Set up compensation measures for written tests. Passing to the next grade may also be temporarily based on general results rather than written exams.



#### **Individual support:**

Offer individualized tutoring by a teaching professional to help pupils catch up academically or progress at their own pace.

## How can classmates support a pupil with cancer?

It's essential that pupils maintain a social link with their classmates.



#### Cards and letters of encouragement:

Regularly encourage other pupils to write cards or draw pictures to express their support, affection and wishes for the child's recovery. Use digital channels to keep in touch (voice messages, videos, robots, etc.).



#### **Hospital visits:**

If authorized by the hospital ward, fellow pupils can visit the child in hospital to spend time with them, which can boost their spirits.



#### Sharing notes and homework:

Offer to share class notes and homework with the child to help catch up academically and stay on top of the curriculum.



#### **Project collaboration:**

Collaborate with the child on school, artistic or cultural group projects, offering them an opportunity to actively participate and feel like they are part of the process.



#### Raising awareness:

Raise awareness of the child's illness among other pupils by organizing information sessions on cancer, encouraging empathy and understanding within the class.



## How can we support teachers?



- · You are not alone in this situation. Other people can support you if needed (colleagues, psychologist, management, etc.).
- It's normal to have questions and doubts. Take care of yourself physically and emotionally.
- It's normal to feel different emotions. Don't be afraid to express them.
- · You must support the pupil as best you can, but you can't do the impossible.
- Don't hesitate to call parents if in doubt, as each situation is unique.
- Talk regularly with the family to evaluate and adapt the child's schedule, homework and participation in various school activities.





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MY NOTES				



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#### Order hard copies of the brochure:

To order paper copies of the brochure: contact@zoe4life.org

#### Additional resources:

The brochure can be viewed and downloaded free of charge on the website of the Centre "Maladie, Mort et Deuil à l'École" of HEP Vaud HEP. Additional resources are also available on this site.

Type "mort-deuil-ecole.ch or cmde.ch" or scan the QR code below and go to the «Cancer brochure» tab.









