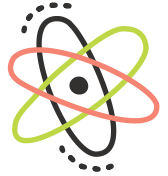
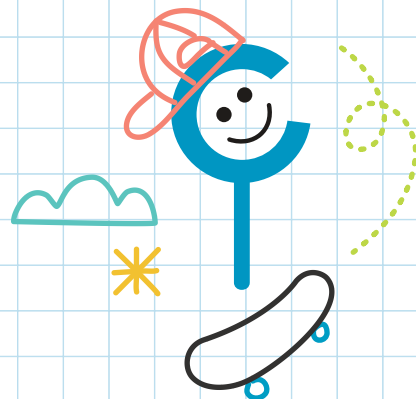




# Students with cancer

A guide for teachers





**Prepared by the Education  
Commission of the Federación  
Española de Padres de Niños con  
Cáncer**

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**Declared of public interest.**

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# 1. Introduction

## 1.1. Federation

The Spanish Federation of Parents of Children with Cancer (*Federación Española de Padres de Niños con Cáncer*, FEPNC) is a non-profit organization, statewide, established in 1990 and declared of public utility on January 8, 1999.

One of the main goals of the Federation is to improve the quality of life at the affective, educational and social level of children with cancer and their families.

The Federation is currently formed by 23 associations located in different autonomous communities.

The Federation is a member of Childhood Cancer International (CCI) – of which it is also a founding member – and of the European Rare Diseases Organization (EURORDIS) at the international level and of the Platform of Childhood Organizations (*Plataforma de Organizaciones de Infancia*, POI) and of the Spanish Confederation of People with Physical and Organic Disability (*Confederación Española de Personas con Discapacidad Física y Orgánica*, COCEMFE), at the national level. Moreover, we collaborate with the Spanish Registry of Childhood Tumors (*Registro Español de Tumores Infantiles*, RETI) and with the Spanish Society

of Pediatric Hematology and Oncology (*Sociedad Española de Hematología y Oncología Pediátricas*, SEHOP).

Currently, the Children with Cancer associations support and provide services to nearly 18,000 people through psychological, social, economic and educational care to children and their families, the provision of shelter for displaced families, as well as research and information and counseling programs.

Since its beginnings, this associative movement has meant a great improvement in the quality of life of our sons and daughters with cancer and, for this reason, one of its main objectives has been to promote the constitution of parents' associations throughout the country. Every year we invest all our efforts to ensure that, in all the autonomous communities, families can count on all our help.

From the experience of the work of these last years and in order to improve the affective, educational and social care, this guide has been updated.



## 1.2. This guide

This guide is intended as a working manual for the education of children and adolescents with cancer, with or without sequelae derived from it.

In addition, it can help in the development of the psycho-pedagogical evaluation of students with cancer, and the development of programs and materials appropriate to the Special Educational Needs (SEN) that may arise from this disease.

As Claudia Grau Rubio, who holds a degree in Philosophy and Letters (Pedagogy) and a PhD in Psychology from the University of Valencia, points out:

**“It is necessary, despite the problems, to provide them [children with cancer] with educational care adapted to their needs so that they can develop an active adult life, despite the disease, its sequelae and the treatments received. Educational care must be an integral part of the medical treatment program and constitute a shared task of parents, teachers and health personnel, since the continuity of the child’s schooling – school, family and hospital – conveys a message of hope for the future; and comprehensive educational care allows the child to develop his or her social and cognitive skills.**

**It is essential to have a well-defined and organized hospital/school program, including: hospital classrooms, educational home care and back-to-school preparation programs, all within the framework of an inclusive school”.**

From these words we can deduce the importance of the return to school for students with cancer; an importance that translates into a sense of continuity in their educational process and in their lives.

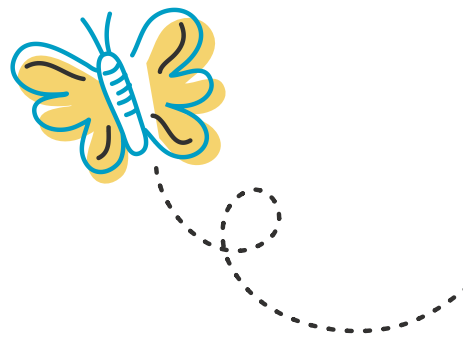
We hope that this guide will serve as orientation and help when intervening and accompanying in the process of treatment and incorporation into the educational center.

## 2. About childhood cancer





Every year about 1,500 new cases of cancer in children aged 0 to 18 years are diagnosed in Spain. Despite being a rare disease, childhood cancer is the leading cause of death by disease up to the age of 14.

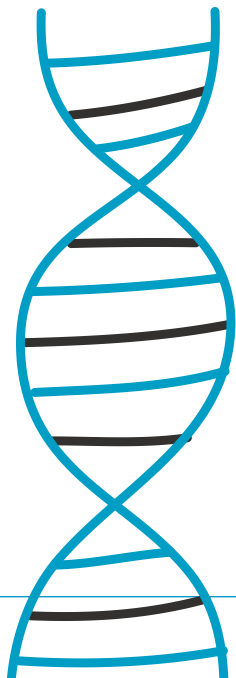


The most frequent type of cancer in childhood is leukemia (27%), followed by tumors of the central nervous system (22.6%) and lymphomas (12.4%), according to the Spanish Registry of Childhood Tumors (RETI). RETI contributes to battle childhood cancer through the study of the survival of children with cancer in Spain and its international comparison, the study of incidence and its trends, and by collaborating in the study of causal risk factors.

The 5-year survival rate for children aged 0 to 14 years has already reached 81%, according to the SEHOP. This is an encouraging figure that aspires to be 100%, since a single death from childhood cancer is too many.

## 2.1. Most common types of cancer in childhood and adolescence

- **Leukemia**
- **Central nervous system tumors**
- **Neuroblastoma**
- **Wilms tumor**
- **Lymphoma**
- **Rhabdomyosarcoma**
- **Retinoblastoma**
- **Primary bone tumor**







### 2.1.1. Leukemia

It is a type of cancer of the bone marrow and blood.

Among childhood cancers, it is one of the most common. Within this type, the most frequent are the acute lymphocytic leukemia (ALL) and acute myeloid leukemia (AML). These types of leukemia may cause, among other symptoms, bone pain, fatigue, weakness, pale skin, bleeding or bruising, fever or weight loss. As they can grow very rapidly, it is necessary to treat them (usually with chemotherapy) as soon as they are detected.

The 5-year survival rate has increased over time, reaching 85%. For children with AML, the survival rate has also increased and is now between 60% and 70%.

### 2.1.2. Central nervous system tumors

This type of tumor is the second most frequent type of childhood cancer.

There are many kinds of brain tumors, with different treatments and prognosis.

Most childhood brain tumors begin in the lower part of the brain, such as the cerebellum or brain stem. They can cause headache, nausea, vomiting, blurred or double vision, dizziness and difficulty walking or handling objects, among other symptoms.

Approximately 3 out of 4 patients with brain tumors (considering all types) survive at least 5 years after diagnosis. The survival rate varies from 95% in the case of Pilocytic Astrocytoma to 20% for Glioblastomas.

## About childhood cancer

### Most common types of cancer in childhood

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#### 2.1.3. Neuroblastoma

About 8% of childhood cancers are neuroblastomas.

Neuroblastoma is an embryonal tumor that occurs in infants and young children, with the average age of diagnosis being two years, considering that 90% are diagnosed before the age of 5 years. It is rarely found in patients older than 10 years.

This type of tumor can start anywhere but is most commonly in the abdomen.

Initial symptoms are related to fatigue and lack of appetite. Later, to the place of origin, for example, swollen belly, bone pain and fever.

Children in the low-risk group have a survival rate of at least 5 years in more than 95% of cases. In the high-risk groups the rate is 40% to 50%.

#### 2.1.4. Wilms tumor

Wilms tumor starts in one kidney, rarely in both.

It is most frequently found in children aged 3-4 years and is rare in those older than 6 years. It accounts for approximately 5% of childhood cancers.

It may appear as a swelling or lump in the abdomen. Sometimes, it may cause other symptoms such as fever, aches, nausea or poor appetite.

The survival rate varies between 38% and 99% (in very specific cases).





### 2.1.5. Lymphoma

This type of cancer starts in certain cells of the immune system known as lymphocytes.

Mostly, this cancer grows in the lymph nodes and other lymphatic tissues such as the tonsils or thymus. Lymphomas can also affect the bone marrow and other organs.

The two main types of lymphoma are Hodgkin's lymphoma (sometimes called Hodgkin's disease) and non-Hodgkin's lymphoma. Both types can occur in both children and adults.

**Hodgkin's lymphoma** is present in approximately 3% of childhood cancers. It is more common in two age groups: early adulthood (between 15 and 40 years of age, usually in people in their 20s) and late adulthood (after age 55). Hodgkin's lymphoma is rare in children under 5 years of age. This type of cancer is very similar in children and adults, as is the treatment applied.

**Non-Hodgkin's lymphoma** accounts for approximately 5% of childhood cancers. It is more likely to occur in younger children than Hodgkin's lymphoma, yet it is extremely rare in children under 3 years of age. The most common types of non-Hodgkin's lymphoma are different in children and adults. This type of cancer often grows very fast and requires intensive treatment, but it also tends to respond better to treatment than non-Hodgkin's lymphomas in adults.

Depending on their location, they can cause various symptoms such as weight loss, fever, sweating, tiredness and lumps (swollen lymph nodes) under the skin of the neck, armpits or groin.

The 5-year survival rate for Hodgkin's lymphoma is 99% for children under 14 years. The survival rate for children with non-Hodgkin's lymphoma depends on the stage of the disease, between 65% and 90%. With intensive treatment, about 90% of children with non-Hodgkin's lymphoma are cured.

## About childhood cancer

### Most common types of cancer in childhood

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#### 2.1.6. Rhabdomyosarcoma

Rhabdomyosarcoma begins in cells that normally develop in the skeletal musculature (the muscles we control to move our body).

This type of cancer can start in virtually any part of the body, including the head, neck, groin, abdomen, pelvis, arms or legs.

It is the most common type of tissue sarcoma in childhood. It represents approximately 3% of childhood cancers and we can distinguish several types: embryonal, alveolar, pleomorphic or anaplastic.

The survival rate in low-risk groups is over 90%. In high-risk groups, the rates range from 20% to 40%. It is important to keep in mind that there are several factors that can change this percentage, such as the patient's age, the site where the tumor develops and the type of tumor.

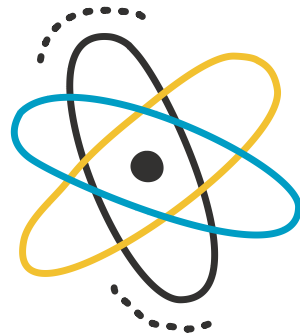
#### 2.1.7. Retinoblastoma

Retinoblastoma is a type of cancer that affects the eyes.

It accounts for 2% of childhood cancers.

It usually occurs in children as young as 2 years old and rarely in those older than 6. Retinoblastomas are generally discovered when their families or medical personnel detect something unusual in the children's eyes..

On average, 9 out of 10 children with retinoblastoma recover, but the prognosis is not favorable if it spreads outside the eye.





### 2.1.8. Primary bone tumor

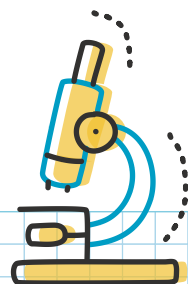
Primary bone tumor occurs most frequently in older children and adolescents, although it can occur at any age. It represents 3% of childhood cancers.

There are two main types of primary bone tumors in childhood:

**Osteosarcoma** is more common in adolescents and usually develops in areas where the bone is growing rapidly, such as near the ends of the bones of the legs or arms. It often causes bone pain that tends to worsen at night or with physical activity. It can also cause swelling in the area around the bone.

**Ewing's sarcoma** is a less common type of bone cancer, which can also cause bone pain and inflammation. It is most usual during early adolescence. The most common sites of onset are the bones of the pelvis (hip), the rib cage (such as the ribs or shoulder blades), or in the middle of the long bones of the legs.

With current treatments, the 5-year survival rate for children with localized osteosarcoma is around 60% - 80%. These cancers are most likely to be cured if they are resectable, meaning if the visible tumor can be surgically removed. For patients with Ewing's tumors that are still localized when first diagnosed, the survival rate is around 70%.



**The primary bone tumor starts from bone tissue and can be malignant (cancerous) or benign (non-cancerous). It differs from metastatic bone tumor, which is a tumor that forms from cancer cells that grow in other parts of the body and then spread to the bones.**

## 2.2. Treatments

The treatment of childhood cancer has evolved over the years thanks to the development of new diagnostic and therapeutic techniques.

There are different instruments to treat the disease, which will be used depending on each specific case.

- **Surgery:** this is the method most commonly used for small tumors located in a specific place; it consists of local excision of the tumor.
- **Chemotherapy:** use of drugs that act on rapidly dividing cells, which is what cancer cells tend to do. However, there are also other non-cancerous cells that also divide fast. Work is currently underway on research into selective drugs that target cancer cells, while affecting healthy cells as little as possible.
- **Radiotherapy:** destroys cancer cells using high-energy radiation. Other areas of the body are protected from receiving radiation.
- **Bone marrow transplantation:** it is a medical treatment that replaces damaged bone marrow with healthy cells. The replacement cells can come from your own body or a donor. The risks and benefits should be discussed in detail with the bone marrow transplant team before the procedure. Each child experiences the diseases differently and a bone marrow transplant may not be appropriate for everyone.



## 2.3. Long-term effects of childhood cancer

The temporary suspension of schooling due to hospitalization implies the alteration of the learning rhythm, which may cause short and long term repercussions. These can be aggravated in some cases by the sequelae of the disease and by the side effects of the treatments.

About 30% of the population who have had childhood cancer suffer serious long-term effects. The treatment each child receives is unique.

Long-term effects also vary depending on the type of treatment used and the dose administered. Other elements that may contribute as risk factors are:

- Type of cancer
- The place in the body where it has developed
- The age
- The child's general health before the cancer
- The child's genetic makeup

In general, the immediate side effects are nausea, vomiting, allergy and general malaise. Radiotherapy and chemotherapy may cause blood disorders.



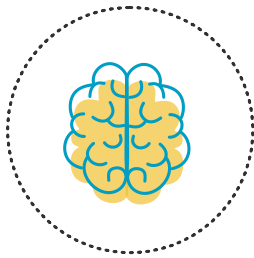
## About childhood cancer

### Long-term effects of childhood cancer

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The treatment is associated with visible physical alterations such as alopecia (it is important to know that it is transitory), amputation of a limb, use of orthopedic devices, weight modification or appetite disorders.

Cognitive alterations may occur, for example, in those brain tumors in which surgery has been necessary to remove certain areas of the brain or when the nervous system has had to be irradiated.



The possibilities for recovery are many and important. In childhood, cognitive functions are not as perfectly localized as in adulthood. The brain is much more plastic, so both spontaneous recovery of neurocognitive functions as well as recovery through rehabilitation and proper work in the teaching and learning process, occurs more rapidly. However, early detection and evaluation of sequelae is necessary for an effective rehabilitation program with the collaboration of specialized services, the educational center and the family.

### 2.3.1. Cognitive and learning difficulties

As survival increases, more studies show that the majority of childhood tumors have neurocognitive disorders due to the direct effect of the tumor itself, as well as to its deficient consequences in the central nervous system after surgery, chemotherapy and radiotherapy treatments. In addition, the appearance of these alterations can occur during the cancer treatment process itself or in the short, medium and long-term after its completion.

Among the main cognitive alterations associated with the disease we find:

- ➔ **Language disorder**
- ➔ **Alterations in short and long-term memory**
- ➔ **Attention deficit**
- ➔ **Information processing alterations**
- ➔ **Executive dysfunction**
- ➔ **Reasoning difficulty**
- ➔ **Other difficulties in cognitive and perceptual areas**





### 2.3.2. When the diagnosis is a brain tumor

A brain tumor is one of the tumors with the highest incidence in childhood cancer cases.

Survival of these cases has increased considerably and constitutes one of the most important challenges for the professionals faced with the task of improving or compensating for the sequelae of the disease and its treatments (mainly cranial radiotherapy).

Due to the structural and functional complexity of the brain, the impact will be different depending on the location of the tumor and the area radiated.

In general, the main cognitive and behavioral sequelae after a brain injury in children and adolescents, and that can also be detected in other tumors, are, over those mentioned above and of greater severity:

#### Cognitive difficulties

- Slowness in information processing, which may also be due to language and communication disorders.
- Increased difficulty in understanding complex sentences and concepts, or associating abstract concepts.
- Reduced problem-solving skills.
- Difficulty in generalizing what has been learned to new situations.
- Difficulty with abstract thinking.
- Concentration difficulty.

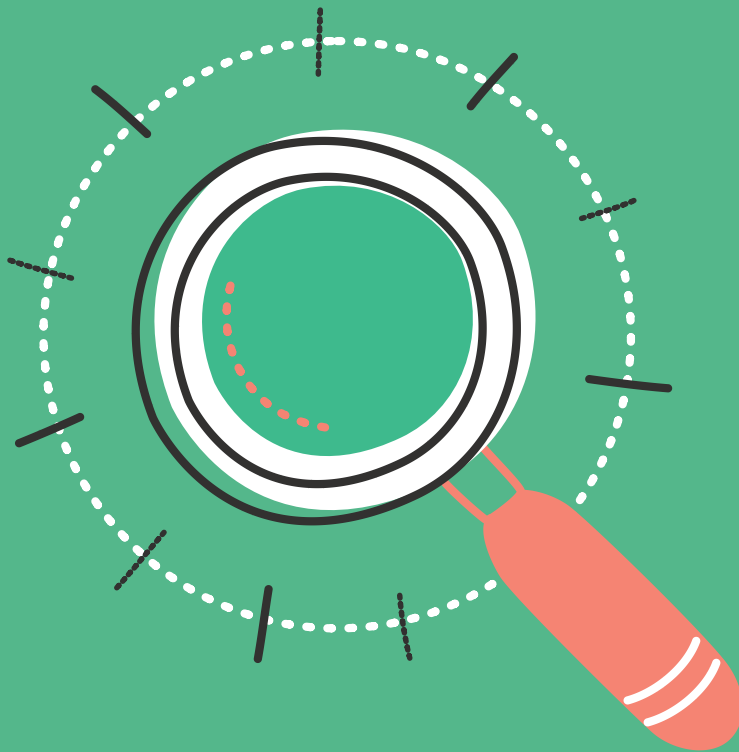
#### Physical difficulties

- Lack of independence in movement due to loss of speed, accuracy or coordination of movement.
- Affectation in the lower or upper limbs.
- Fatigue.

#### Psychological and social difficulties

- Lower frustration tolerance, which can lead to outbursts of aggression and increased social isolation.
- Apathy and poor involvement in tasks.
- Difficulty in relating to peers.

### **3. A cancer diagnosis at school age**





## 3.1. How it affects according to the educational stage

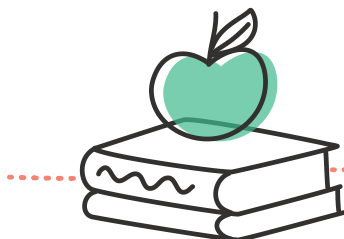
The diagnosis of cancer has a profound impact on the lives of children and their family structure, causing behaviors and emotional reactions that influence the individual and group functioning of the family.

As a consequence of the disease process, alterations may occur in their physical, cognitive and emotional development; acceptance by the peer group, the development of body image, and the child's and adolescent's idea of themselves, which must be adequate for them to feel good about their appearance.

In adolescence, the development of a sexual identity and value system, as well as planning for the future, is particularly important.

One of the main changes during this process is the separation from their family, social and school routine due to treatment and hospitalization, which implies having to cope in an environment that is unfamiliar and may be perceived as hostile.

The emotional manifestations they express can be very diverse and must be understood taking into account the relational variables within their family unit. The task of the teaching staff, together with the different professionals involved in this process, is to handle all reactions patiently and creatively. However, some aspects may be common depending on the age and developmental stage.



## A cancer diagnosis at school age

How it affects according to the educational stage

### Early childhood education stage: 0-6 years

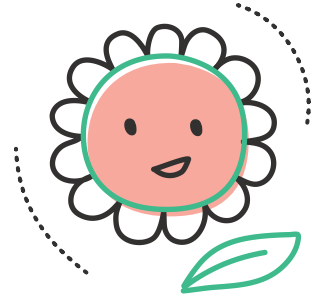
Children at this stage tend to interpret the world on a very specific level. They are not able to understand the meaning of their diagnosis or the reasons why they must endure medical treatments, but they do recognize which part of their body is sick.

Since magical thinking is present at this stage, it is important to offer sincere and concrete answers in literal language to the curiosity they express.

The symbolic function has a great development in this phase. Through symbolic play they incorporate what surrounds them and thus show us their inner world.

They need to know that they are not the cause of their illness, and that cancer is not contagious or a punishment.

The situation will be more difficult for them as they will have to be separated from their parents at the beginning, and they will feel more dependent and insecure.



#### Reactions that may appear at this stage:

- ➔ **Anxiety about separation from parents during medical procedures and hospitalization.**
- ➔ **Fear and upset by painful medical procedures.**
- ➔ **Shouting, crying, resisting cooperation or withdrawing.**
- ➔ **Holding on to their families.**
- ➔ **Aggressive behavior.**
- ➔ **Feeling angry or sad because they can no longer play or explore as they normally did.**
- ➔ **Insecurity/fear of returning to school.**
- ➔ **Isolating from their peer group.**



## Primary Education stage: 7-12 years

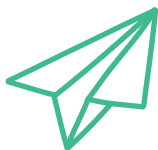
At this stage, there are advances in social relations and in the objectification of thought.

The sense of cooperation may appear at this time, so regulated games begin to be fun. Integration with peer groups is essential for the development of social skills and the expression of feelings.

Curiosity about death appears and progressively they begin to realize the social implications of their illness. This will lead to a greater awareness of the change in their image, of their illness and death, and of the changes in their social environment.

### Reactions that may appear at this stage:

- ➔ **Being upset by the disruption of their school routines.**
- ➔ **Decrease in academic performance.**
- ➔ **Missing both their classmates and friendships.**
- ➔ **Feeling anger and/or sadness about losses in their health, school and normal life.**
- ➔ **Feeling guilty for causing the illness.**
- ➔ **Concern that cancer may be contagious.**
- ➔ **Seek more emotional and social support from family and peers, or else social isolation.**
- ➔ **Concerns about death.**
- ➔ **Anxiety.**



#### Secondary Education stage: 12-16 years

At this moment they can perform formal operations and they can already understand and assimilate knowledge about their disease and treatments.

Their main fears are those of most of their peer group: loss of control, being different from the rest or being discriminated against, or being ignored by their peers. Their reactions are increasingly focused on relationships and concerns for the group and the long-term consequences of their illness. They find the possibility of facing their death more difficult, showing concern for their future.

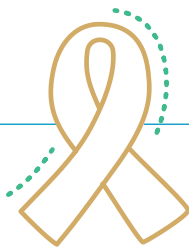
Adolescents are very conscious of their physical appearance and are very susceptible to social rejection. They have doubts about whether to let other adolescents know about their disease, for fear of feeling different or being rejected.

Therefore, adolescents may experience feelings of fear or anxiety about going back to school. They worry that they will not be able to do school activities and are saddened that they will not be able to do sports as they did before the disease. They find it hard to see that it is temporary.

At this age, when they are striving to develop their independence, they will find themselves increasingly dependent on their family members as well as on the medical personnel who care for them.

#### Reactions that may appear at this stage:

- ➔ **Being upset by the disruption of their school life and group activities.**
- ➔ **Feeling that their independence is being eroded.**
- ➔ **Intense emotional reactions.**
- ➔ **Require the support of friends, schoolmates and other important people in their life.**
- ➔ **Reflect on the meaning of life and the effect cancer has on their identity.**
- ➔ **Adopting risky behaviors.**
- ➔ **Harmful substance abuse.**
- ➔ **Thinking about death and suicide.**
- ➔ **Rebelling against their parents, the interdisciplinary team and/or treatment.**



## High school: 16-18 years

At this phase, adolescents are fully aware of their disease and its short, medium and long-term consequences. They require the support of their friends, classmates and other important people in their lives.

They reflect on the meaning of life and the effect cancer has on their identity.

It is a very delicate moment since at 18 years they are in a stage of decision-making about their academic and professional future, and it can be altered by the disease. It is vitally important that the necessary school support is provided to avoid disruption of the school year.

For adolescents and their families, receiving support from the educational center is beneficial throughout the disease process. To this end, it is necessary to facilitate communication channels that allow continuity with their peer group, as well as with the teaching staff. The center must be informed, as far as possible, in relation to the child and their needs.

All this will facilitate not only the adaptation during this process in the most normalized way possible but also the subsequent reincorporation into the center and its activities. In addition, it is necessary to work in parallel with the classroom, to also advise the group during this process and to take care of the link between the class and the child and adolescent.

### Reactions that may appear at this stage:

- ➔ **Suicidal or self-harming ideation.**
- ➔ **Insomnia and lack of appetite.**
- ➔ **Lack of interest in regular activities.**
- ➔ **Not finding pleasure in things that used to be enjoyable.**
- ➔ **Emotions interfere with daily activities.**
- ➔ **Confusion.**
- ➔ **Anxiety.**
- ➔ **Uneasiness.**
- ➔ **Harmful substance abuse.**
- ➔ **Poor academic performance.**
- ➔ **Excessive concern for their academic future (university entrance, vocational training, higher level training cycles).**
- ➔ **Self-image concerns.**
- ➔ **Feelings of failure and low self-esteem.**

## 3.2. Diagnosis: the first moments

When a diagnosis of cancer arises in the educational center all the staff should be informed and kept abreast of the evolution of the disease.

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After being informed, the center must design educational programs appropriate to the different phases of the disease and that should be carried out in coordination with the teaching team involved in their care.

It is important to keep in mind that both teachers and the classroom need to go through a process of adaptation to the new situation to provide adequate support. To do this, they must have sufficient information that allows them to objectively assess the situation. They also need to express their emotions and doubts, so that they can act in a way that encourages a sense of normality in the activities and the treatment of the child with cancer.

### Suggestions for the first moments:

- ➔ Respect confidentiality and the information that the family wishes to transmit.
- ➔ Count on the guidance and advice of the associations of Children with Cancer in their autonomous community, to gather all information about the type of disease.
- ➔ Adopt a positive attitude that will be projected onto the child or adolescent.
- ➔ Coordinate the work among teachers to consider students with cancer, as far as possible, as the rest of the students.
- ➔ Encourage connection with the school.
- ➔ Motivate students to maintain their relationships to avoid isolation behaviors.
- ➔ To keep communication channels open, both in person and through the Internet (ICT).





### 3.3. Hospitalization and convalescence at home

The hospital stay should be kept to the minimum necessary so that hospitalization periods do not last as long as they used to.

The aim is to ensure that children do not leave their environment during the disease process so that they lose as little contact as possible with the basic parameters of their usual life (home, family, school, friends...).

The demand for information on the part of their parents is increasingly higher, they want to “know” in order to “participate” in the process their child is going through and thus cope with the situation. This makes their involvement in the different aspects of the treatment more effective, gradually helping in the acceptance of the disease.

At the beginning of the process, education is considered secondary to the central issue: medical treatment. Subsequently, once treatment has begun, a certain normalization takes place and education becomes important in several ways: to avoid the curricular gap to ensure educational continuity and to reduce the feelings of fear and anxiety that are manifested in the child and adolescent and that influence their state of mind. All this for two reasons:

**1- School continuity conveys a message of future perspective and a sense of belonging.**

**2- Educational care allows them to develop their social and cognitive skills.**

Hospital classrooms play a key role in the child's developmental process. Playing and communicating with their peers, besides offering educational follow-up, provide a place of evasion and elimination of tensions.

The hospital teaching staff and the home care team should coordinate with the tutor of the reference school to achieve optimum efficiency, periodically reviewing their work during home care, to promote an adequate teaching-learning process.

This communication and the one that can be established with the student will help maintain their identity as a member of their class group.

Convalescence is defined as periods in which hospitalization alternates with staying at home without being able to attend school. Many cases can be of long duration. During this stage, the time spent in the hospital will be attended by the hospital classroom and during the period at home, home care will be requested from the educational administration, or contact the associations of parents of children with cancer in each autonomous community.

## **What teachers can do**

- + Communicate with the family and inform them of the situation.**
- + Maintain fluid communication with the family to favor the teaching-learning process.**
- + Assign a teacher from the reference center to be the link between the teaching staff and the other educational agents involved (hospital classroom, home teachers, etc.) to establish a periodic coordination that facilitates the organization.**
- + With family consent, and in collaboration with them, it is advisable to inform the class about the situation of the absent partner, always taking into account the knowledge of the children with cancer about what is happening to them. Associations of parents of children with cancer can advise and collaborate in any intervention of the educational community.**



- + Adapt the academic curriculum to the difficulties caused by the disease.**
- + Carry out the necessary interventions in the classroom with students and teachers through talks and guidelines that help to learn about the disease and its effects to develop empathy regarding the situation.**
- + Motivate students to maintain their relationships, thus avoiding withdrawal and isolation behaviors (letters, video calls, sending drawings, photos, messages...), always respecting the child's privacy in social networks.**
- + Going back to school implies a normalization of their situation, a return to the school routine, to interacting with their classmates, etc. At this time, it is important to plan and monitor the incorporation to ensure a positive and beneficial return to school.**

## 3.4. Getting back to school

The path to be taken after the convalescence period must be adapted to the recovery time, age, educational stage and the disease itself.

It is important that, prior to the reincorporation, the family can provide the reference center with updated information on the child's condition so that the appropriate measures can be taken to meet their needs.

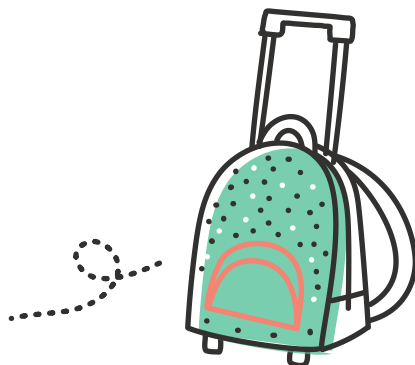
These measures can be related to aspects of accessibility (for example, if he/she had to use a wheelchair) or of a methodological nature (materials with letter enlargement), so that the center is aware of the situation and can address it at each stage.

Knowing the consequences caused by some types of cancer is fundamental to identify and attend all side effects (fatigue, slow processing speed, attention or memory alterations, impulsive, uninhibited and defiant behaviors – a consequence of surgeries or brain tumors – motor and sensory difficulties, etc.). Knowing the child before diagnosis provides very relevant information to be able to contrast the current state as well as to define progress, without forgetting an exploration of the correspondence between chronological and mental age.

This information must come from the family (or with their permission), through the

collaboration of the Spanish Federation of Parents of Children with Cancer and its associations, who can provide specific information, guidelines or resources to help teachers to intervene in this unexpected situation.

It should not be forgotten that the period of reincorporation involves a time of adaptation and communication among all, respecting the rhythm of the students.





### Steps to follow at the school

- 1.** Gather all the information on the current situation of the child in order to adjust the needs to his/her new academic pace.
- 2.** Inform teaching staff and peers about how students with cancer are doing, especially in cases of greater difficulty or limitation, so that they can empathize with their new condition.
- 3.** Give the student with cancer the opportunity (if he/she deems it necessary) to explain his/her story at school.
- 4.** Normalize the situation by promoting group belonging and solidarity.
- 5.** Encourage a gradual incorporation according to physical needs (providing support from the center to cover those classes that cannot be attended).
- 6.** Take the appropriate measures by the center and its teachers. Know what resources are available to meet new needs (curricular, accessibility, etc.).
- 7.** Observe and evaluate their development to continue adjusting the educational response according to their evolution.
- 8.** Offer a space where teachers and students can solve doubts or collaborate with and for these minors.
- 9.** Inform the family of any changes related to improving the quality of life of the child with cancer in and out of the classroom.
- 10.** Request help and collaborate with the associations of families of children with cancer in each autonomous community.

## 3.5. Classroom intervention

The advice and guidance of associations of relatives of children with cancer to collaborate in each phase facilitate the approach to these cases.

Throughout the disease and treatment process, it is important to maintain normalization and empathy with each child. Intervention and awareness in the school environment, both with their peers and with the rest of the students, will provide them with appropriate educational strategies that will guarantee normalization throughout the process from diagnosis to school reincorporation.

It is necessary to establish talks and/or meetings; either with the educational team or with the students, being appropriate for the interdisciplinary coordination of the educational agents, and the psychoeducational interventions of group awareness with the students.

The educational team involved throughout the illness requires attention and support to facilitate interaction with their students, communication with the family and coordination with the rest of the teachers involved (hospital teachers, home care teachers).

### How to promote this support and care?

- ➔ **Procuring spaces and times for grouping teachers which facilitate emotional support and accompaniment among teachers.**
- ➔ **Observing the group-class (behavior, attitudes, questions...) which will help the students to process the situation positively.**
- ➔ **Facilitating the transmission and reception of all the information received by “treating” it with care and adapting it to the students.**
- ➔ **Requesting help and specific attention whenever they consider it appropriate. The Spanish Federation of Parents of Children with Cancer (FEPNC) and its associations will provide this care.**



## Educational Team

### Self-care for teachers



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≈ It must be assumed that there are no good or bad emotions, but each one will be trying to express something.

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≈ Having clear and truthful information helps to better organize the situation and make educational decisions about it.

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≈ Addressing these cases without fear is the first step to moving forward progressively. These approaches and interventions should not fall on the teaching staff of reference, but it is the work of the educational team for the whole community (students, teachers and families).

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≈ Working as a team and in a coordinated manner helps to eliminate the anxiety that this situation can cause among the teaching staff.

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≈ Expressing feelings with peers and external professionals can help to manage emotions (since these are rare cases in the school environment) and to understand how they cope with these situations, developing strategies to compensate for them.

## Students

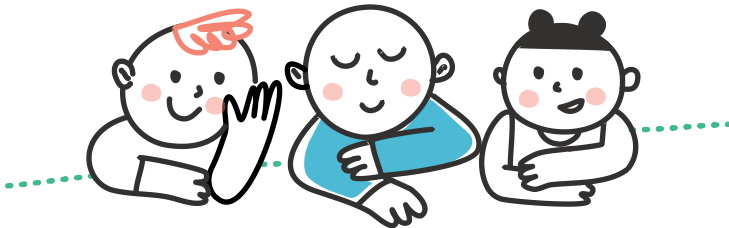
In childhood and adolescence, they may have unrealistic ideas or doubts about cancer, so it is appropriate to give them support with a language and understanding suitable for their age. To do this, they must know that the peer has the disease. Not knowing it can cause them not to understand physical, psychosocial, cognitive changes or curricular adaptations. Sensitizing the rest of the class facilitates the child's reincorporation, avoiding demotivation and reinforcing their self-esteem and self-confidence.

Any information communicated to the students must be known by their parents. The information should be accurate and truthful and should provide an opportunity to discuss other related issues.

### How students can help:

**It is necessary, prior to incorporation, to inform pupils of the possible physical, cognitive or behavioral changes, so that this information helps them to understand the new situation and their needs in the classroom; giving them information to better comprehend the disease and how it affects them (talks, stories, videos, dynamics, etc.) and thus share doubts, experiences or concerns.**

- ➔ **Treating him equally, without overprotection.**
- ➔ **Helping them with homework and day-to-day tasks in the classroom.**
- ➔ **Adapting to the new rhythm.**
- ➔ **Keeping in touch when absences occur again.**







## 3.6. Resources and materials

Each educational stage requires an explanation of the disease appropriate to the level and maturity of the students.

Several resources for working on childhood cancer (stories, videos, games, etc.) are presented below, and activities are proposed to be carried out in the classroom depending on the educational stage.

### Early childhood Education

In Early Childhood Education, information about the disease is communicated through stories, simulation games, corners, creative activities, songs...

Some of the materials that serve as a guide to introduce children to childhood cancer awareness and empathize with children suffering from this disease are:



**Reading children's stories that immerse the child in the context of the hospital and the illness helps to understand the situation.**

#### *Toby y la máquina voladora (story)*

This story can facilitate the child's adaptation to the disease, especially concerning hospitalization and the break with everyday life. It emphasizes the importance of friendship.

#### *Berta reúne fuerzas para afrontar el cáncer (story)*

Berta is a little girl suffering from cancer. Thanks to all the people around her, everything is much easier.

#### *Wiky-2, el pequeño robot (videogame)*

Interactive game that, through three different games, develops in a clear way key concepts to understand their disease, treatments and side effects, as well as practical tips to minimize their effect.

## Early Childhood Education

### Proposal for classroom activities

#### Sticker booklet

Booklets with stickers that simulate hospitals, doctors, materials, ailments... To facilitate the knowledge of medical materials and their use, as well as promoting the approach to care and healthy habits.

#### Children songs

*A mi burrito le duele...*,  
*Seguiremos* from Macaco,  
*Canción de los Derechos Humanos*,  
from Unicef.

#### TEY doll (You are me, Tú Eres Yo)

Children become responsible for their care, and through it, they can express their emotions.

#### Teddy Bear Hospital

Each student takes a teddy bear to school with a temporary disability situation (headache, arm fracture, etc.) and there, together with the doctor, they cure it. To do this, they will go through five workshops: teddy bear consultation, teddy bear operating room, nutrition and hygiene, the human body and defenses.



### **Toy medical kit**

To become familiar with medical equipment (thermometer, syringe, etc.) and procedures (analysis, x-rays, etc.). The teacher can show the objects and ask what is this, what it is for, or can also ask what we use to know that we have a fever, and then show it.

### **The triplets hospital**

Elena has become ill and her parents and sisters have to take her to the hospital, where she soon recovers. A pop-up game book full of details so that the little ones can get to know what a hospital is like, have fun inventing their own stories and become brave ambulance drivers.

### **Traveling book "Trotamundos"**

Create a book or notebook to send drawings, letters or messages to their partner when he/she is at home or in the hospital. The teachers will be in charge of making it travel.

### **Vadim el Pirata: Reading and related activities.**

Story presentation and group reading. Several scenes from the story can be handed out for them to color, order the sequences of the story, paste them on cards, etc.

#### Primary Education

In Primary Education, information about the disease is transmitted through stories, simulation games (first and second courses) and creative and/or artistic activities. Dialogue and debate should be encouraged to resolve any doubts. The explanation will be clear and with short messages about the disease and treatment.

Communication is established through a dialogue or debate in which aspects such as what cancer is or what changes it can produce should not be missing; looking for naturalness and feelings of acceptance and empathy, through questions such as: how would you want to be treated if you were ill, how do you feel when you are next to a sick person?

#### *Gasparín Super Químio (story)*

A cartoon created by a young patient at the Royal Marsden Hospital in Great Britain. The character Gasparín Super Químio fights cancer cells with the help of chemo.

#### Video

#### *En el país de los dragones (story)*

A story that explains, through a fantastic fable about dragons, the process of the disease and its treatments.

#### *La mejor medicina (story)*

A story aimed at children without cancer (it should be read by an adult: family members, teachers...). The objective is to create a positive attitude towards the child with cancer that favors their integration and improves their quality of life.

#### *¿Por qué, Charlie Brown? ¿Por qué? (video and story)*

Video made by Charles Schulz with the Peanuts characters (Charlie Brown) to raise awareness about leukemia and teach them about the behaviors to adopt.



***Wiky-2, el pequeño robot (videogame)***

Interactive game that, through three different games, develops in a clear way key concepts to understand their disease, treatments and side effects, as well as practical tips to minimize their effect.

***La pecera de los cuentos (story)***

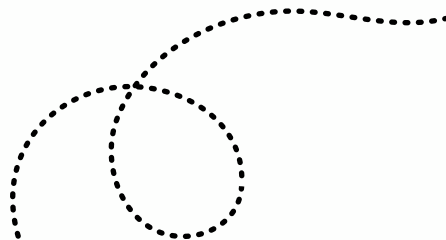
Pecerín, through stories, shows children the hospital environment to help them lose their fear of it.

***Lina la pequeña golondrina (story)***

It is a story aimed primarily at children going through cancer. They will be able to identify with Lina, the swallow protagonist of this story, because she will also go to the wise tree (doctor) and the fir tree (hospital).

***Roberta la ardilla se explica de maravilla (story)***

A friendly squirrel aims to bring "leukemia" closer to the little ones to make it easier for them to understand what is happening. To do this, it begins by telling about blood cells and their functions and then links it to the disease, its treatments and consequences. It ends with a series of tips on how to take care of the body and be healthy.



## Primary education

### Proposal for classroom activities

#### Supermara, superheroína por sorpresa (story)

Individual or group reading of the story. Fragments of the book are selected, interpreted and ordered sequentially, identifying which illustrations they correspond to. A cape is made, where the handprints of all classmates and teachers are written, along with words of support, encouragement, etc., thus symbolizing the ability of the child with cancer to face each treatment by wearing it.

#### Toy medical kit

The material will be completed with more specific tools (masks, gloves...) to become familiar with medical equipment (thermometer, syringe, etc.) and procedures (analysis, X-rays, etc.). The teacher can show the objects and ask: what is this, what is it for, or: what do we use to know that we have a fever?, and then show it to the students.

#### Puppet show Libro de aventuras

A pop-up book in which each page is an adventure with a different landscape. In her dream, a little girl goes from one adventure to another pursued by a monster that is there, chasing her, but not seen. When he finally catches up with her, they fight in "single combat" and he defeats her. The little girl wakes up and tells her dream, her journey through a wild world, her flight through the clouds, her trip to the bottom of the sea, her leading role in a puppet theater... she tells that she has defeated the monster... that she will defeat all the monsters that life puts in front of her. A story that tells us about overcoming life's problems.

Story.



### Science workshop

Students are divided into five groups and rotate through five locations: Medical Library, Laboratory, Intensive Care, Children's Hospital and Examination Room. Each group carries a passport and when they have completed each phase they will get a mark on their document. They will wear an ID with their name on it and each ID will be the color of their corresponding group. At the end of the activity, they are given a scientist diploma and have their photo taken at the photocall.

### Un aplauso (video)

It conveys a message of optimism to ill children, as well as to their families and friends.

Video.

### Miscellanea

Other resources and activities that can be proposed to students and that require group participation and favor the normalization of the disease, treatment, hospitalization, medical personnel... would be: creation of collages, murals, invention of a tale or story, staging of a hospital, etc.

### Secondary Education and High School

The Secondary Education and High School stages require more time for the transmission of information and the resolution of doubts. Communication is established through role-playing games and situations; in addition to setting up a dialogue or debate in which aspects such as what cancer is (awareness and information campaigns) or talking about changes that may occur should not be missing; all this looking for naturalness and feelings of acceptance and empathy, or asking questions such as: how would you want to be treated if you had a disease? What attitudes help you to cope better with the disease? It would also be interesting if minors who have overcome the disease could actively participate by telling their personal experience.

It is advisable that all the readings, videos and activities are worked on at the appropriate times, dedicating tutorials, discussion spaces..., that favor empathy with their peers with cancer and allow reflection.

#### *An obstacle race* (comic-exposition)

A story that tells the experience of a young man diagnosed with leukemia.

“Carlos, we have to hospitalize you. You probably have leukemia”. This is the beginning of what will become an obstacle for Carlos, a 16-year-old boy who one day is diagnosed with leukemia. During his stay at the hospital, Carlos will meet Cristina, another girl with leukemia who will be helpful during the hospitalization; tests and treatments he hardly knew anything about; and he will receive support from family, friends, professionals and associations for children with cancer.

*Soy Daniel* (video, comic-guide)  
DVD comic and guide for adolescents diagnosed with cancer. The aim is to favor adaptation to the disease and facilitate dialogue between the adolescent, the medical team and the family.

*Mi primer año como pelón* (video)  
Elías, through his personal experience, tells us about his process to overcome leukemia, transmitting a message of positivism and hope.

Through my camera (*A través de mi cámara*) (photo report)  
Cancer captured in photos by the ASION veterans group.





### **Movies**

There are several films related to childhood and juvenile cancer. Some of these are: *Maktub*, *Declaration of War*, *My sister's Keeper*, *Letters to God*, *The 4th floor*, *The Fault in Our Stars*, *Camino*, *Ways to Live Forever* and *Now is Good*.

### ***Mi héroe*, from Antonio Orozco (videoclip)**

The song *Mi héroe* tells a story of overcoming and hope. It is a tribute to all the anonymous people who get up every morning and face life: "Heroes are heroes because nobody knows they are".

### ***Cumplevidas* (short film)**

A short film based on real stories and emotions, starring twelve teenagers with cancer. If the birthday is the anniversary of a person's birth, the "transplantiversary" is a very special event: the celebration of each year of the transplant. A very significant moment.

### ***Pulseras rojas***

Series that depicts the situation of a group of teenagers with cancer.

### ***¿Qué le preguntarías a un niño con cáncer?***

A video of teenagers with cancer answering questions about the disease.

[Video](#)

### ***¿Qué me está pasando?* GUIA ASIÓN PARA JÓVENES Y ADOLESCENTES CON CÁNCER.**

Guide to help children and adolescents suffering from cancer to understand the process they are undergoing and to help them overcome it.

[Guide](#)

## Secondary education and High school

### Proposal for classroom activities

#### Exhibition of the comic

##### *An obstacle race*

There are 28 A3 sheets to be exhibited in the school, where the students will see them and later comment them in class, asking their teachers about the subject. Through the exhibition, they will see the disease as an obstacle course, full of difficulties that will have to face to reach the goal. Some of these obstacles can be fear, misinformation, uncertainty, etc.

#### Video about the comic

##### *An obstacle race*

The previous activity can be accompanied by a video about the creative process of making the comic. The author of the comic and its protagonists, Carlos and Cristina, who were in charge of the dialogues, are presented. The whole process can be seen: the documentation, sketches, pencils, color proofs, etc.

#### Role-playing

In class, a staging of the comic *An obstacle race* can be proposed, where the students will assume the role of the characters. With this activity, they will put themselves in the shoes of each character and will understand entertainingly the process of the disease; from the first symptoms, hospitalization, support and the various situations experienced by the protagonist and his family.



### Video-forum

One of the films previously mentioned (*Maktub*, *Declaration of War*, *My sister's Keeper*, *Letters to God*, *The 4th floor*, *The Fault in Our Stars*, *Camino*, *Ways to Live Forever* and *Now is Good*) will be chosen to watch in class and then dialogue, so that students can raise their doubts and comment on what they have felt, what sensations the movie has transmitted to them, etc.

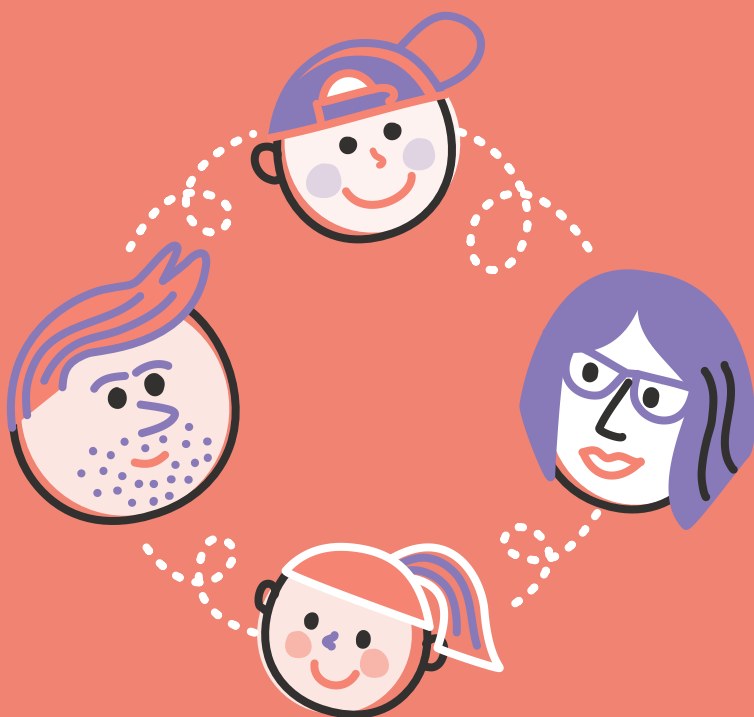
### Songs

Through music, complicated life situations will be identified and solutions will be sought for the negative messages they transmit, trying to involve and empathize.

### Dialogues or discussions

These should include aspects such as what cancer is and talk about the changes it can produce, seeking naturalness, acceptance and empathy. Questions can be asked, such as: how would you want to be treated if you were ill? What attitudes help you to cope better with the disease? It would be interesting if young people who have overcome the disease could actively participate by telling their personal experiences.

## **4. Attention to the family in the educational center**





## The diagnosis of cancer in a son or daughter is a great stress and imbalance in the whole family unit.

In addition to enduring the emotional “shock” that comes with the disease, new situations arise, such as:

- ➔ **Temporary absence of a parent to accompany a daughter or son with cancer.**
- ➔ **Change of roles in the distribution of tasks (work, care of the affected child as well as the rest of the children...).**
- ➔ **Family adjustment concerning treatment, which sometimes involves other family members in school care.**
- ➔ **Parents often become overly protective or more lenient to children's educational duties.**
- ➔ **They are likely to be anxious and uncertain about their child's return to school. When this happens, they tend to worry about possible infections and fatigue, which may occur when they return to school.**
- ➔ **They are also concerned about possible student reactions to the child and obvious side effects such as hair loss or weight gain.**



Likewise, the rest of the family also suffers alterations. Changes in routine, frequent separation from the family, being in the care of other family members, and the uncertainty of this new situation are aspects to be taken into account during this process.

The reference center and, in particular, the teaching staff and guidance services, become fundamental figures in supporting family members in school.

At the onset of the disease, they may be approached by other classmates who have heard rumors. All this leads to reactions and problems may hinder their school and social development.

Efforts must be made to accompany as fully as possible. The teaching staff must be aware of the situation.



Among the common reactions that may occur, the following stand out:

- **Concern for the sister or brother who has the disease: the information received may be limited or even biased at the beginning of the process and may lead to misconceptions. They may be especially concerned on treatment days.**
- **Concern for their parents: siblings, especially older ones, feel the need to support them or simply not to be a burden. The absence of parents due to treatments and hospital admissions is also a cause for concern and sometimes leads to emotional deprivation.**
- **Academic or behavioral problems.**
- **Physical symptoms, such as stomachache or headache.**
- **The most common feelings can be: sadness, jealousy, isolation, guilt and anger.**



## How the school can help

### A

#### Parents

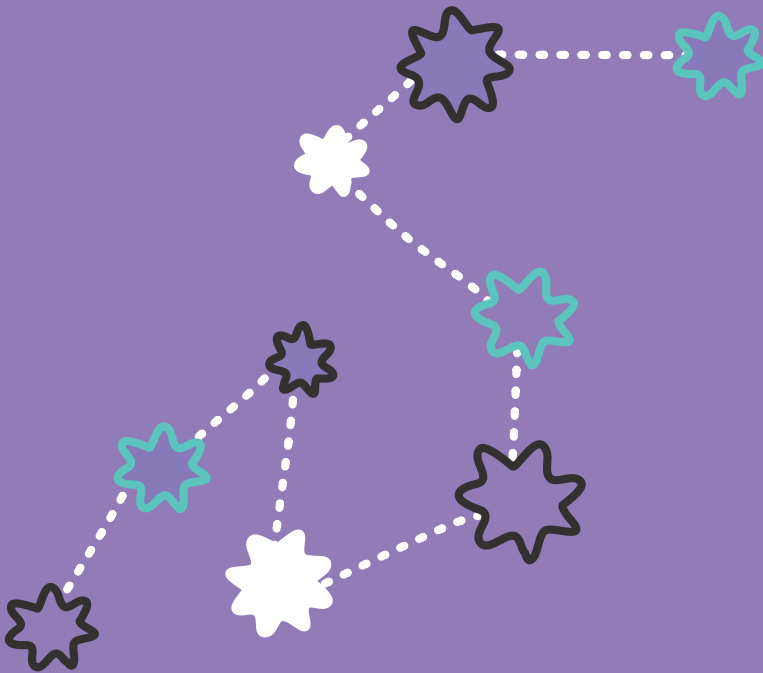
- Being receptive to the information they want to transmit.
- When the diagnosis is known, contact them and show interest in the evolution of the disease. You are a significant person to them.
- Continuous contact during the disease.
- Inform them of how the situation will be addressed with the rest of the students and take into account their wishes.
- Inform them of the activities to be done in the classroom and involve them whenever possible, adapting the activities to their needs.
- When the return to school approaches, hold a new meeting to clarify aspects of the current situation to favor the best adaptation to the school.

### B

#### Siblings

- It is convenient that the closest teachers are aware of the information available to the sister or brother about the disease in order to be able to accompany them in the most appropriate way.
- If the teacher detects a lack of information or misconceptions about something related to the disease, contact the family and/or its reference association and consult all the doubts in order to carry out the best approach.
- Perform group-level intervention with the entire class if needs are observed by any party.
- It is advisable that a member of the teaching staff committed to attend more directly to the sibling of a student with cancer.
- The school is the ideal context to involve him/her in his/her care, offering him/her responsible tasks such as taking home the homework and notes, establishing contact with his/her family, etc.

## 5. Advanced illness and grief







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## There is a growing awareness of the need to respond to situations of loss.

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In this section, we will focus on giving some general guidelines for those cases in which the children have advanced cancer or have died. From the **Pedagogy of Death and Grief**, this approach is called the “post or palliative approach”; however, one does not educate for losses only at the time they occur. The “preventive approach” i.e., the incorporation of pedagogical actions that happen regardless of whether there has been a significant loss, facilitates the grieving process because there has been a previous emotional rapprochement.

Advanced disease means a disease with a gradual, progressive and incurable course, unresponsive to available curative treatments which will evolve towards death in the short or medium term in a context of progressive frailty and loss of autonomy. It is usually accompanied by multiple symptoms and has an emotional impact on the sick person, his or her relatives and the health care team. When death is expected to occur in the short term (days, weeks), the term “terminal illness” or “terminal condition” is also often used.

In this phase of the disease, they receive palliative care, which helps to mitigate pain and other symptoms and provides spiritual and psychological support from the time of diagnosis until the

end of life and during grief. In this sense, they are part of the continuum of cancer care, becoming especially relevant when curative treatment is no longer the goal of care and the focus shifts to quality of life. The term “end-of-life care” does not necessarily imply that the end of life is near but rather that it is expected.

From the educational point of view, reaching this stage should not be linked to the idea that all work ceases, but should be seen as a new way of caring for the child or adolescent and his or her family. Addressing these cases from the first moments with the student and his/her classroom should be the responsibility of the whole educational community. Therefore, creating spaces in the center for the expression of emotions and the exchange of ideas or activities helps to elaborate a rare situation and would mean, more than ever for these students and their families, support that even if it could not be in person, it would exist and be felt.

## 5.1. Advanced disease and end of life

One of the most key aspects of childhood and adolescence is school or high school and this situation does not change when children have a life-threatening or life-limiting illness.

In addition to providing basic knowledge or learning and meeting needs such as socialization or achievement, attending school conveys the idea that you continue to be a significant member of society.

Sometimes, educators or family members, with the best of intentions, determine that the school is not appropriate without taking into account the wishes or needs of each child. The attitudes of parents, teachers or classmates may determine the quality of the experience at the school. Likewise, their desire not to attend or the circumstances in which their health conditions must be respected.

As stated in the document “Pediatric palliative care in the National Health Care System: Criteria for care” (*Cuidados paliativos pediátricos en el Sistema Nacional de Salud: Criterios de atención*), “to contemplate the child as a person implies understanding the multidimensionality of a subject that has its own identity and dignity, belongs to a specific culture, holds or assumes a series of its own or family values and is supported by a network of human, material and spiritual ties. To take care of him in an integral way supposes, therefore, to take into account both the objective problems

and the needs that he presents and manifests in the different spheres of his person: physical, psychological, spiritual, social”. The criteria of the palliative care teams contemplate care both at home and in the educational environment or social service centers (if they are in care or guardianship), provided that the resources are available to carry them out. In this way, the aim is to maintain the normality of family and social life without interrupting their daily activities.

Inclusion in the classroom when the disease is advanced requires interdisciplinary, structured and adequately coordinated care. If communication is important at all stages of the disease, it plays a fundamental role at this time.

What differentiates the death of a child with an advanced disease from other causes (sudden death due to accidents or trauma) that could occur during the school year is the factor of time. The near-death of a student gives the educational community time to prepare the most appropriate response to each particular case. Although it is recommended that the school has an action protocol to deal with these situations, the response to this situation is highly individualized.

Often, simple measures can improve a child's well-being. If they are too tired to stay in the



classroom all morning, they may benefit from going to class for a few hours at a time. When his energy wanes, it is a good idea to adjust assignments accordingly. If the child had lost a lot of weight, they may find uncomfortable to remain in the chair and it may help to use a cushion or pad. The teacher may also has an area in the classroom where you can rest or a support person in case of reduced mobility, vision or hearing loss, etc.

Not only the student but also parents, teachers and classmates – with their unique and different needs – must be taken into account. If the family prefers to keep the progression of the disease private this should be respected. Their parents will be in charge of providing information about the child or adolescent's situation, about what he/she knows and what he/she wants to be transmitted. For them, having the child attend school can be an added source of stress due to the fear of a medical emergency occurring and they may even feel that they lack the tools to deal with the situation. On the other hand, the rest of the students may have questions or concerns about their friend or the disease. Communication will always be open and honest, trying to answer their questions. In this way, they will have the opportunity to establish a warm and healthy relationship based on empathy, understanding and compassion. Even when the child is unable or unwilling to attend the center, you can always maintain the bond through letters, cards or drawings, videos, calls, etc. Lack of contact may be perceived as incomprehensible indifference. Whether you are at the center or at home and wish to receive visitors, it is important to take hygienic-sanitary measures.

They may receive negative comments from their peers or pressure to keep up with the pace of the class. In these cases, well-trained and emotionally prepared teachers, guidance team and management team as well as continuous communication during the whole process transmit security to their mothers and fathers, facilitating assistance and normalization. To this end, it is advisable to do some personal work beforehand since death mobilizes many emotions.



Throughout the disease process, there is a progression toward the end-of-life phase that calls for a permanent assessment of the situation, adapting the response to each moment and redefining objectives and needs, with great sensitivity, creativity and flexibility. A frequent question is when to stop the educational intervention. The answer is as wide as the variety of people involved. It is important to remember that we will always take into account their wishes and needs, and that physical conditions do not always determine the quality of the educational experience.

In this situation educational care can consist of reading or listening to a story, poem or history; playing quiet music; sharing memories, thoughts or emotions; or any other activity that is of interest to the child and that allows him to continue learning, interacting and achieving. Meeting your needs is not incompatible with the time you have left to live. The result is very enriching for the person with the advanced disease and for his or her family, students and the entire educational community, as it provides them with an invaluable experience. This approach places LIFE at the center and the idea of making it as meaningful as possible until the last moment.



## 5.2. Grief in the classroom



### a) Evolution of the concept of death in children

The concept of death is an abstract and complex term that will develop progressively and depends on very diverse aspects such as age, culture, education or the emotional characteristics and previous experience with death. The components of the understanding of death are:

- 1.** Death affects all living beings (universality).
- 2.** After death one does not live again (irreversibility).
- 3.** After death, the body ceases to function and our vital functions cease completely (non-functioning).
- 4.** Death does not depend on our thoughts and/or desires (causality).
- 5.** After death, a part of the person does not continue inside the physical body, according to some religious beliefs (non-corporeal continuity).

**The grieving process** in childhood and adolescence is determined by age or personal development. Emotional reactions after the death of a partner will be determined by different aspects such as the existing relationship and/or bond with the deceased, previous experiences with death, etc.

Some of the most common characteristics that can occur at each educational stage are:

#### **Preschool education stage (0-3 years)**

- ➔ Inability to understand the concept of death and difficulties in communicating their needs verbally.
- ➔ Insecurity and suffering due to the absence/separation from the deceased (feeling of abandonment).
- ➔ Irritability, sleeplessness, crying and protesting behaviors.

#### **Early Childhood education stage (3-6 years)**

- ➔ Consideration of death as something temporary (no concept of irreversibility).
- ➔ Egocentric thinking can generate the idea that death is a product of their thoughts/desires or that they have done something wrong that has caused it.
- ➔ Mood characterized by temper tantrums, irritability, ambivalence, regressive behaviors, physical discomfort, alterations in sleeping and eating patterns, nonspecific fears and continuous search for proximity to adults.



### Primary Education stage (6-12 years)

- Complete acquisition of the concept of irreversibility (they know the life cycle of living beings and that it ends with death).
- Gradual acquisition of the concept of causality, so they can still fantasize about the idea that death may be caused by some event related to them. However, at the end of this stage, they can already consider their own death, grasp the meaning of the rituals surrounding it and have spiritual/religious doubts.
- Reaction to death similar to adults: fear and vulnerability to death, denial of feelings about death as a protective mechanism, anger and aggression towards the family/ social environment, decreased school performance or difficulties expressing feelings about the loss.

### Secondary Education stage (12-16 years)

- Full acquisition of the concept of death, like an adult (universality, irreversibility, functionality, causality).
- Perception of death as something alien and of no concern at this stage of life. Conversations about death mainly with peers, with great ambivalence in emotions and behavior.
- Significant behavioral changes, isolation and loss of interest, feelings of guilt and increased conflict, approaching risky activities/ behaviors and possibility of taking on the role of the deceased person.



#### **b) Main actions of teachers in case of grief**

In the case of death due to cancer of children in our educational center, it is necessary to evaluate several aspects that will significantly determine the probability of successfully carrying out an intervention related to grief.

Thus, it would be essential to take into account several aspects:

- 1.** To have the opinion and consent of the family (whenever possible) in the realization of this type of activity, in addition to knowing the degree of collaboration before such actions.
- 2.** Probe the opinion of the rest of the students' families regarding the information and intervention to be carried out with their children about the death of one of their classmates.
- 3.** Attitude and predisposition on the part of the center and its teachers to carry out this kind of intervention.
- 4.** Resources, tools and training available to the center and its teachers to carry out an intervention of this type.

For this reason, the following are some of the most vital actions to be carried out by teachers in the event of grief in the classroom, which will favor the healthy development of this process:

- ➔ Inform the family about those actions that will be carried out in the classroom/center and propose their collaboration and/or participation in some of them if they consider it appropriate.
- ➔ Respect any emotional expression or absence of it on the part of their peers, helping them to identify the emotions.
- ➔ Work with the rest of the colleagues on the doubts that may arise about the situation, without judging them and giving sincere explanations (not lying) and adapted to their understanding.
- ➔ Control rumors that may arise among students after the death, giving real and objective explanations.
- ➔ Maintain the usual daily routine and school dynamics whenever possible, always taking into account the possibility of making the classroom/center schedule more flexible whenever deemed necessary.





## Activities that facilitate grief in the classroom/educational center

The following are some examples of activities that can serve as guidelines for a collective approach to grief in the classroom and/or school.

- ≈ Holding an assembly where we can talk freely about the deceased person, the memories and experiences he/she left us, what we think and feel about his/her death, etc. This activity must always be led by teachers prepared not only to direct it (topics to be addressed, explanation of doubts, respect for what each person has expressed) but also to “collect” and manage in a healthy way the emotions expressed.
- ≈ Attendance at the wake, burial or funeral at the time of death. Visiting the cemetery or place where the ashes “rest” after the death (it is essential to respect the personal decision to participate in them, as well as to inform about the possible situations/contexts/environments that can be found in them).
- ≈ To write poems and messages whose content is related to the deceased person (memories, feelings of gratitude, etc.) to carry out some ritual about his/her memory (burning their messages and throwing them to some significant place; putting the messages or their ashes in a balloon and releasing them into the sky; exposing them on a remembrance panel for a while, etc.).
- ≈ Memory box. It is about finding a physical place where to deposit memories. It can be photos, drawings, gifts... The elaboration and filling of this box will also allow you to express feelings, remember experiences and talk about the partner who is no longer there.
- ≈ Celebration of significant dates related to the deceased (e.g. birthday).
- ≈ Reading stories and/or watching movies that deal with the subject of death. There are numerous films that deal with grief and loss in childhood/adolescence, with some focusing specifically on childhood death due to illness or cancer.
- ≈ A trip of remembrance. A trip to nature, a walk or a visit to a place important to the deceased companion can be organized. Once there, there are many possibilities: planting a tree, leaving a remembrance sign, etc.
- ≈ Celebrate acts of remembrance or homage such as reading a letter or poem, unveiling a plaque or planting a tree at the school, etc.

#### c) When to use an external professional? Warning signs.

Grieving is a natural process that involves many factors such as age and relationship with the deceased, reason and circumstances of the death, family and/or social support network, etc.

The combination of these may cause difficulties for their healthy development, in which case is recommended not only to carry out a more constant monitoring/attention of the students' reactions but also to turn to specialized professionals if necessary.

However, it is key to note that the warning signs listed below do not occur across the board, and it is common for children to react to loss naturally. In addition, they may be caused by other personal and/or family situations of the student that will have to be assessed. We suggest contacting the child grief specialist of the nearest association of Children with Cancer when any of the following warning signs persist over time and interfere significantly with the normal functioning of the student in any of his or her areas of reference (family, educational, social, etc.).

#### Symptoms:

- ➔ **Emotional numbness concerning the loss. The person is disinterested, apathetic and even insensitive to any aspect related to the deceased partner or the relationship/ experience with him/her.**
- ➔ **Depressed mood characterized by feelings of hopelessness, desire not to go on living, self-injurious actions, etc.**
- ➔ **Prolonged withdrawal and/ or loss of interest over time in social relationships and/ or leisure activities that motivated him/her before the loss.**
- ➔ **Excessive concern for the health and/ or safety of others, especially primary attachment figures.**
- ➔ **Avoidance behaviors about the deceased (e.g. not staying in places shared with the deceased: room, school, etc.).**
- ➔ **Significant increase in somatic complaints (e.g. headache, stomach pain, etc.) sustained over time with no clinical cause to explain them.**



- ➔ Aggressive behaviors, feelings of guilt or deep sadness prolonged in time, often accompanied by anxiety, difficulties in sleeping or concentrating, etc.
- ➔ Performance of behaviors typical of life stages that have already passed (episodes of enuresis or encopresis, speech typical of the youngest children.
- ➔ Risky behaviors that may endanger their health and the well-being of their close environment (drug use, risky sexual behaviors, dangerous leisure activities....).
- ➔ Significant changes in school performance, refusal to attend school, isolation from peers, etc., maintained for a prolonged time.
- ➔ Upon request.



Finally, the death of a student from cancer in an educational center also has an emotional impact not only on the rest of the students but also on the teaching staff and other members of the educational community who have had a relationship with the deceased. In addition, they are not only affected by the loss and elaborating their grief but they also carry out on multiple occasions tasks of accompaniment and care of the grieving process of their students. Therefore, understanding and emotional closeness between the teaching staff, guidance and management teams, sharing feelings, memories, etc. or going to the appropriate professional when one feels it is necessary, sometimes provides relief and is a healthy and advisable way of dealing with such loss.

## 5.3. Educational resources



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# Federated and partner associations





## Andalucía

### Asociación de Padres de Niños y Adolescentes con Cáncer de Almería y Provincia (ARGAR) Centro de Servicios Múltiples de la Diputación

Ctra. de Ronda, 216. 04009 – Almería.  
Telephone number/Fax: 950 257 594  
Email: [argar@argar.info](mailto:argar@argar.info)  
Web: [www.argar.info](http://www.argar.info)

### Asociación de Padres de Niños con Cáncer de Jaén (ALES)

#### Villacarrillo

C/ Ramón y Cajal, 8. 23300 – Jaén.

#### Jaén

C/ Úbeda, número 6, sótano derecha.  
23008 – Jaén.

Telephone number: 696029721 / 606191737  
Email: [ales\\_jaen@hotmail.com](mailto:ales_jaen@hotmail.com)  
Web: [www.asociacionales.com](http://www.asociacionales.com)

### Asociación de Padres de Niños con Cáncer de Andalucía (ANDEX)

Castillo de Alcalá de Guadaira,  
18 bajo B. 41013 – Sevilla  
Telephone number: 954 23 23 27 – 954 23 80 01  
Fax: 954 29 88 48  
Email: [info@andex.es](mailto:info@andex.es)  
Web: [www.andexcancer.es](http://www.andexcancer.es)

### Asociación de Madres y Padres de Niñ@as Oncológic@s de Málaga (ASPANOMA)

La Regente 35. 29009 – Málaga.  
Telephone number: 669 343 212

Email: [Info@aspanoma.com](mailto:Info@aspanoma.com)

Web: [www.aspanoma.com](http://www.aspanoma.com)

### Asociación de Madres y Padres de Niños Oncológicos de Granada (AUPA)

Avenida Juan Pablo II N°74, Edificio Valparaíso  
2, Piso 4ºB. 18013 – Granada  
Telephone number: 609 54 76 91  
Email: [hola@asociacionaupa.com](mailto:hola@asociacionaupa.com)  
Web: [www.asociacionaupa.com](http://www.asociacionaupa.com)

## Aragón

### Asociación de Padres de Niños Oncológicos de Aragón (ASPANOA)

#### Zaragoza

Calle Duquesa de Villahermosa, 159.  
50009 – Zaragoza.  
Telephone number: 976 45 81 76  
Fax: 976 45 81 07  
Email: [aspanoa@aspanoa.org](mailto:aspanoa@aspanoa.org)  
Web: [www.aspanoa.org](http://www.aspanoa.org)

#### Huesca

Carretera A- 1211 Tardienta - Almudévar, s/n.  
22270 – Almudévar (Huesca).  
Telephone number: 974 25 08 52  
Email: [aspanoa.almudevar@aspanoa.org](mailto:aspanoa.almudevar@aspanoa.org)  
Web: [www.aspanoa.org](http://www.aspanoa.org)

## Castilla- la mancha

### Asociación de Familias de Niños con Cáncer de Castilla-La Mancha (AFANION)

#### Albacete y Cuenca

Calle Cristóbal Lozano, 15. 02002 – Albacete.  
Telephone number: 967 510 313.  
Email: [afanion@afanion.org](mailto:afanion@afanion.org)  
Web: [www.afanion.org](http://www.afanion.org)

### **Ciudad Real**

Avenida Pío XII, 20.  
13002 – Ciudad Real.  
Telephone number: 926 21 24 03  
Email: ciudadreal@afanion.org  
Web: [www.afanion.org](http://www.afanion.org)

### **Toledo y Guadalajara**

Avenida Río Boladiez, 1, bajo.  
45004 – Toledo.  
Telephone number: 925 25 29 51  
Email: toledo@afanion.org  
Web: [www.afanion.org](http://www.afanion.org)

## **Castilla y León**

**Asociación de Padres, Familiares y Amigos de Niños Oncológicos de Castilla y León (PYFANO)**

### **Salamanca**

Calle Vaguada de la Palma, 6-8. 2A.  
37007 – Salamanca.  
Telephone number: 923 07 00 23

### **Valladolid**

Edificio Rondilla. Calle Rondilla de Santa Teresa s/n despacho 114. 47010-Valladolid.  
Email: info@pyfano.es  
Web: [www.pyfano.es](http://www.pyfano.es)

## **Comunidad de Madrid**

**Asociación Infantil Oncológica de Madrid (ASION)**

Calle Reyes Magos, 10. Bajo.  
28009 – Madrid.  
Telephone number: 91 504 0998  
Email: asion@asion.org  
Web: [www.asion.org](http://www.asion.org)

## **Comunidad Foral de Navarra**

**Asociación de Ayuda a Niños con Cáncer de Navarra (ADANO)**

Calle Ermitagaña, 13 – trasera bajo.  
31008 – Pamplona (Navarra),  
Telephone number/Fax: 948 17 21 78  
Email: adano@adano.es  
Web: [www.adano.es](http://www.adano.es)

## **Comunidad Valenciana**

**Asociación de Padres de Niños con Cáncer de la Comunidad Valenciana (ASPANION)**

### **Alicante**

Calle Martin Luther King s/n (esquina Adolfo Guixot) bloque 3, local 1. 03010 – Alicante.  
Telephone number: 96 591 03 78  
Fax: 96 524 59 56  
Email: alicante@aspanion.es

### **Valencia**

Calle Isla Cabrera 65 bajo.  
46026 – Valencia  
Telephone number: 96 347 13 00  
Fax: 96 348 27 54  
Email: valencia@aspanion.es  
Web: [www.aspanion.es](http://www.aspanion.es)

## **La Rioja**

**Asociación riojana de familiares y amigos de niños con cáncer (FARO)**

Calle San Antón, 6-2ºA.  
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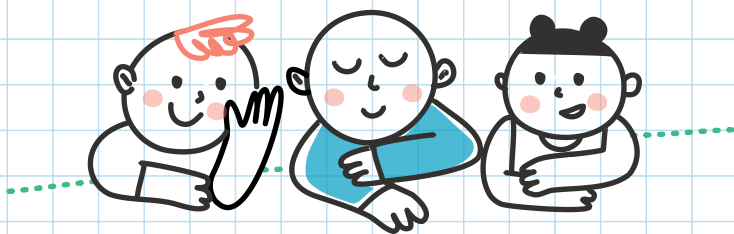
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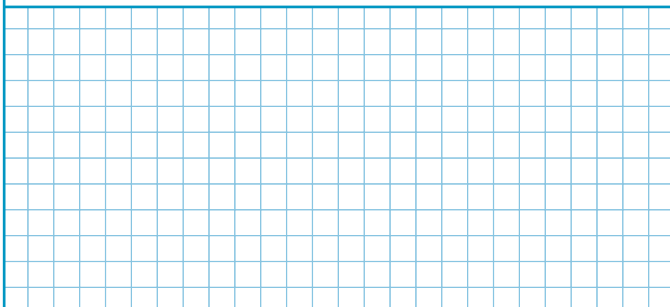
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