



RAiISE

RAISING AWARENESS OF INVISIBLE ILLNESS IN SCHOOLS & EDUCATION

The
**RAiISE Awareness
Support Guide**



Contents

- ② Introduction
- ⑤ Top Tips
- ⑧ Strategies
- ⑩ 16 Communication
- ⑩ 18 Before a Diagnosis
- ⑩ 20 New Diagnosis
- ⑩ 22 Unpredictability of Illness
- ⑩ 24 Attendance
- ⑩ 26 Exams
- ⑩ 28 Privacy
- ⑩ 30 Mental Health
- ⑩ 33 School Trips
- ⑩ 34 Case Study
- ⑩ 36 Raising Awareness and Fundraising
- ⑩ 37 Support from Charities





Introduction

Welcome to the **RAiSE Schools pack!**

We hope this guide helps you find answers to questions about supporting young people with complicated health conditions which are often 'invisible'.

There will be countless young people within your school who will be living with life-changing conditions; often they will be suffering in silence, given that so many conditions are 'invisible'.

'**Invisible illness**' is a phrase we use throughout this pack which refers to conditions that, whilst having a large effect on people's day to day lives, might not be immediately obvious.

Here at **RAiSE**, we aim to highlight the fact that not all illnesses can be seen. We hope you are introduced to key strategies and tips which will help you to support your young people, without taking up vast amounts of time.

Our Background:

RAiSE was founded by Sophie Ainsworth following her experiences with the autoimmune disease lupus which she was diagnosed with when she was 14.

After struggling to get the right support in school and meeting with other young people in a similar position, it became clear that many conditions were being overlooked because of their 'invisible' nature.

Throughout the production of this pack, the input of young people and families has been pivotal. In all stages of development, we have worked with young people with a variety of invisible illnesses of all ages and backgrounds, as well as their parents, teachers and health professionals.

We would like to say a huge thanks to all involved for their commitment and honesty when sharing their experiences and opinions on our work. ❤️

Our Aims:

- 🎯 Educate and help school staff to support young people with invisible illnesses
- 🎯 Raise public awareness of invisible illnesses to improve understanding
- 🎯 Empower and support young people to take control of their illness and care



Keep your eyes peeled for quotes from young people, parents and teachers

Values and Beliefs:

We believe that all young people have the right to a high-quality education and the potential to achieve.

It is essential that support is provided where needed to ensure that young people's health care goes beyond the hospital doors or prescription boxes, reflecting the reality of chronic illness influencing all aspects of life.

We are also aware of the pressures and time constraints put on teachers and hope that this pack is concise and easy to use, offering simple tips and changes which can be implemented in the classroom, with minimal addition to your workload.



"I need space to rest and somewhere to sit quietly really helps me"

Young person aged 13

"My daughter knows she can leave her class at any time to go and talk to her named support if she feels unwell or needs anything"

Parent



"I always make sure that I can have time to talk in a quiet place. I can help the young person try to understand and accept their condition and build resilience"

Primary school teacher





Top Tips

Respect



- ⊗ **Respect** the young person's wishes – ask them if they want people to know about their condition or not.
- ⊗ The young person will know their condition and their body better than anyone else. It is important to **trust** what they say about the severity of their condition on any given day.
- ⊗ You might find it helpful to research the specific condition to give you a deeper **understanding** of their difficulties.
- ⊗ The young person needs to know that they can **trust** you. Anything they feel they can share with you must only be shared with appropriate adults as absolutely necessary (unless it's a child protection issue).

Talking to the Young Person




- ⊗ Be aware of where and when you choose to **talk** to the young person about their health.
- ⊗ Try to use a **neutral tone** when talking to the young person about their condition. It's good to empathise, but don't overdo it.
- ⊗ **Talk** to the young person on their level – treat them as the expert they are!
- ⊗ Be aware that no two conditions and indeed, no two people with the same condition, are the same. It is important to **listen** carefully to the individual circumstances of the young person.

Communication



- ⊗ It is helpful for the young people to have a member of staff as their 'go-to' person regarding their health. This works best if the young person can choose the member of staff they feel most **comfortable** with.
- ⊗ A flexible regular meeting time is useful, for the young person and their chosen member of staff to touch base and **talk** through successes and issues.
- ⊗ Equal **communication** between the young person, parents and teachers is important. This could be an update by email or a phone call to parents at an agreed time.
- ⊗ Most healthcare professional teams are very willing to **talk** to teachers about a young person (with consent given) in order to help them to navigate their school life. Take advantage of this opportunity if it is available.



“Having a specific member of staff who is responsible for her wellbeing is helpful. We know they will keep an eye on her and have a good understanding of her condition”

Parent

Practical Issues



- ⊗ It is important to **understand** that many conditions are unpredictable, so a young person's needs can vary day to day and even hour to hour.
- ⊗ Often, when coping with an invisible illness, the young person can look healthy whilst in reality feeling very unwell. This is one of the biggest barriers to **understanding** in the school setting.
- ⊗ Pastoral care has to be a priority. Although time is limited for pastoral staff, it is key to the young person's **wellbeing** to be able to access appropriate pastoral care if and when they need it.
- ⊗ Young people may need **simple practical changes** to make a big difference to their day, such as: access to a lift key, access to a chill out room or moving classrooms if the location presents a problem.
- ⊗ Discuss the individual young person's **needs** with them and their parents.
- ⊗ Sometimes a very simple change can make a huge difference to the **wellbeing** of a young person with an invisible illness.
- ⊗ An initial meeting after diagnosis or upon entry into school is very important to establish the **needs** of the young person. This could involve the use of the Health Passport found in this pack and a verbal agreement about the **support** that needs to be given to all parties.
- ⊗ All parties need to **update** each other with changes and stick to the plan!



Strategies

There are various methods and strategies staff members can use and to **help** a young person with an invisible illness. Often these methods can also be used with all young people with health conditions, visible or otherwise.

As a staff member, the strategies you put in place can make a big difference not only to a young person's school life, but their home life. It may take time for them to **acknowledge** the change in their lifestyle.

Communication



Communication is essential in working with young people and their families; it is important to remember to always be open and never promise things you cannot guarantee.



"People don't take the time to understand something that doesn't affect them"

Parent

Many of us are unaware of how people **feel** with an invisible illness, and because they can't **see** a physical problem, they believe that the person is okay when in actual fact they are not.

Here are some methods that you can use to **communicate** better with young people and their families:

🕒 Tailored communication plans

By **listening** to each young person individually, you can tailor how they receive information from school if they are out of school due to medical appointments or symptoms.

🕒 Encourage peer to peer communication

Friends are an important part of the **support** network of a young person living with an invisible illness. Sometimes they can help to promote **understanding** and tolerance around the stigma of living with a long term hidden disease. As in life, friendships can be difficult and it may be necessary to **help** with communication between friends.

By **motivating** friends to spend time outside of school together, this can **help** the young person to have some time for themselves and a chance to enjoy friendships without thinking about their illness.

🕒 Email

Arrange to use email to **communicate** with young people and parents where appropriate when a young person is not able to come to school. Always check that all concerned are happy with this.



“We always keep in touch with parents by email about treatment updates. Then, when we are talking to parents in the playground or at the end of the day, we are talking about normal, everyday things like any other parent”

Teacher

🕒 Sending work home

If **email** is not available, post work to the young person's house so they can keep up to date with their studies.

🕒 What should and shouldn't be said

It's important to remember that, as the teacher of a young person with an invisible illness, you are not expected to know or understand everything about their condition. Indeed, saying that you understand can sometimes sound patronising or false, because it is unlikely to be true. Instead, it's better to be **open** with the young person about what you do and don't know.

One of the most common things teachers say is that they **understand** the young person and know about their illness, which is probably not true. The family and young person will only themselves be starting to **understand** the illness.

Teaching Styles



It is important to make sure you are **aware** of your teaching style to fully engage and support all young people in your class.

You can alter your style by:

🕒 Building adaptations into lesson plans

Planning is key to any lesson but by actively being **aware** that there may be young people whose illnesses mean they need more accommodations, you can plan this at an early stage and see where will be best to incorporate this in the lesson.

"Her teacher was so tuned in... without us ever having to mention to him that her medication had changed, he had already noticed a positive change within weeks of her starting her new medication"

Parent



🕒 Identifying learning styles

When meeting with the young person and their family to **discuss** plans for their school life, it would be good to discuss their **learning style** and how they find it best to take in information. From these meetings, you can put together a specialised plan that will aid the young person.

🕒 Recording class discussions

Many lessons involve group participation. If the young person is missing lessons where they cannot be involved, you could consider **recording** class discussions (with appropriate consent) so the young person at home can see how their peers perceive the topic they are learning about.

Trust Strategies



🕒 Relationships

The key is to build **trust** straight away and build a relationship with the young person and family. By creating a reliable network in the school, it will be easier to **communicate** and make contact when they need **support** or advice.

🕒 With the young person

Ensure any communication with the young person about their illness takes place in an **appropriate location**, in the presence of people who share their confidence. Do not discuss personal details in an open corridor or in front of their peers.

“My son was so upset that he was not believed. A teacher should never say that a young person is pretending”

Parent



🕒 Parents

Working with parents/guardians and keeping in touch to **discuss** the young person's progress within school will build **trust** and allow them time to relax and trust that the young person is **safe** and **happy**.

Understanding the illness/condition and the variability of symptoms

You do not need to know about an illness to **support** your young person, by just showing you're willing to **listen** and **understand** that each illness has different symptoms and they can change at any time.

Empowerment and Acceptance



🕒 Acknowledgement of lifestyle and the change to the young person

It is important to **encourage** and **empower** the young person, as their illness may have knocked their confidence. By **listening** to them, you can **support** them with this change in their life. For example, if a young person who used to take part in after school clubs/activities has been diagnosed with an illness that means they do not have the energy to continue with those clubs, they will be disappointed. They may not understand why they can no longer take part, and they may be frustrated by the limitations they are facing.



"It's not good being questioned all the time... trust is a really big thing"

Young Person, aged 14

🕒 Health Passport

One thing that may be of use is allowing the young person to complete a **health passport**. Our specially designed Health Passport can be downloaded from our website.

This can be kept on them and shared, when needed, with staff, to show that a young person may need extra **help** or alert them to symptoms that may be a warning sign.

🕒 Self-management

Once the young person **understands** their illness, it is important for them to begin to learn how to self-manage, i.e. when they need their medication, or how to deal with symptoms when they arise. The Health Passport can be a tool to discuss your role in their self-management.



“Emma’s support teacher got to know her very well. Emma absolutely trusts her”

Parent

Practical Strategies



🕒 Quiet Room

This a quiet place which can be used by young people to take a break from the main hustle and bustle of school life when they are feeling unwell.

For young people who have suppressed immune systems, it is important, that this is not the nurse’s room, where they may be exposed to too many germs.

⦿ Mobility/ moving around

Allowing young people to leave class earlier enables them to take their time to get to their next class. This will **relieve** the pressure of the transition between lessons, which can sometimes be busy, confusing and crowded. It also allows young people the privacy to take a few minutes to themselves.

⦿ Seating arrangements

Ask the young person if sitting in a particular part of the classroom will **benefit** them. This may vary depending on the young person and the specific **needs** of their condition.

⦿ Lift pass

Provide lift passes when applicable. This will **help** young people who have mobility issues due to their illness.

⦿ Lockers

Young people may be unable to carry textbooks or materials given by teachers. Allowing an onsite locker can **help** the young person to **manage** their textbooks and materials.



“Sometimes I’ve found that teachers are impatient because I’m a few minutes late arriving at class. The reason is usually that I’ve had to walk a distance or climb stairs and I struggle with this”

Young Person

🕒 'KiT' meetings

'Keeping in Touch' meetings are essential for not only the young person but their parents. It is important to make sure all parties are **updated** with both problems and successes alike. **Positive encouragement** will go a long way.

🕒 Passes to leave the room

Many schools have rules against young people accessing certain areas or going to the toilet within class time. A pass allows a young person who needs it to '**access all areas**', including corridors or toilets which may be off limits to other young people. Passes can be downloaded from our website.

🕒 Fundraising

Later in this booklet, there are ideas on fundraising to help the school as a whole **support** young people with illnesses and to **raise awareness** of different illnesses. Fundraising, although doubtless well meant, should always be undertaken sensitively and with full consultation with the young person involved. While some young people may welcome fundraising or awareness drives, others may find them embarrassing or overwhelming. Do not name any individuals unless they agree.



"When I say I need a break, it's hard to be questioned about it and it makes me feel awkward because it's difficult to explain. I feel like I'm not being believed"

Megan, aged 15



Communication

Young people don't want pity or to be patronised, but to be **listened to** and **believed**.

Treat what the young person says with **respect**. **Trust** them.

Remember that the young person is often the expert on their own illness. They are the best person to let you know how it is best managed. Ask questions such as 'What can we do to help you in school? What would you like to see happening in school? How would your ideal school day run?'

Talk to young people with **empathy**, but don't overdo it. The young person may tell you things that are potentially upsetting or shocking, but you need to keep calm and neutral in order to be able to **help** them and reduce the student's sense of being different.

The young person should be able to choose a teacher or other member of staff that they feel **comfortable** with as opposed to being told to go to pastoral care or head of year.

Scheduled catch ups will **help** the young person to know they have the **time** and **space** to discuss any issues or just a general chat. It may **help** them to be able to 'park' issues temporarily when they know there will be an opportunity to explore them at an agreed time.

The designated teacher should also liaise with parents and touch base with them at an agreed interval – even if there is no immediate issue. Personalise the type and frequency of the **communication** according to the parents' wishes.

Explore the possibility of **talking** to a healthcare professional who is trained in the particular illness. In particular, specialist nurses, occupational therapists, physiotherapists, and youth workers are **willing** to chat to staff to ensure school life is as straightforward as possible.

Be aware of **where and when** you talk to a young person or parent about their illness. Young people/parents may not want to talk in front of the class or on the corridor.

Ensure the entire staff team is aware of the healthcare plan.

Be aware that **communication** by standard letter or text to parents is not always appropriate and can come across as aggressive and showing a lack of empathy. For example, receiving letters from the Attendance Officer highlighting the importance of attendance for academic success, pointing out poor attendance and giving an expectation of improvement is not helpful for someone with a chronic illness.

Use email, Teams/Zoom, Powerpoint, links to videos, podcasts or virtual learning platforms to enable young people to keep up with classwork.

If possible, use school administration systems to highlight young people with hidden illnesses, so that even office staff can have an **awareness** when sending out letters or information.



Before a Diagnosis When a young person is trying to find out what is going wrong

Sometimes it can take a long time to actually get to the bottom of a **health** issue with a young person. They can feel very sick and unwell while trying to put on a **brave** face and look like nothing is wrong.

Every young person will handle this differently but many will feel scared, **worried** and confused.

This can affect school life in many ways, such as behaviour, concentration and attainment.

There's **no need to wait** for a diagnosis to implement a support plan. You can use the Health Passport available to download on our website as a tool to explore what support is needed. This can be revisited as time goes on, but could be a good way to offer support at a worrying time.



"School have never made an issue about attendance. They know she's at school as much as possible and when she can't be she will do her best to catch up"

Parent

Attendance can also be affected with many hospital and doctors appointments.

Showing **understanding** can make all the difference to a family. It can be good to let the office staff be aware that things are a little different to avoid any mix ups.

It may be an idea to gently check from time to time that things are progressing and offer **support** if needed and wanted by the family. This will can also be a stressful time for parents too.

Communication between school and family will make a huge difference before and during the time of diagnosis. Keeping in touch, listening and showing **understanding** is important for everyone involved.



“Time extensions help to give an opportunity to move around and stretch a bit half way through the exam”

Secondary school teacher



New Diagnosis



When a young person is diagnosed with a new condition, the most important thing is to be friendly, **approachable** and sympathetic. It's okay not to know everything about the illness or conditions you are hearing about.



A meeting should be held to discuss the medical support and needs. This **could** be attended by the Headteacher, SENCO, pastoral care leader or a teacher the young person trusts.



It's a good idea to allow the young person to choose a teacher whom they **trust** who will be their first point of contact. This could be any member of staff who the young person feels most comfortable with. They can organise regular, informal meetings as frequently as the young person wishes.



Plan how you are going to help by **discussing** with the young person their individual needs. It could also be really beneficial to do a small amount of reading about the condition – your young person will really appreciate this!



Create a **Health Passport** for the young person, or an individual healthcare plan. You could use the template on our website, or there is one available on the government website.



With permission from the young person, make sure the school staff are informed of any **adjustments** or support that might be needed. If a young person doesn't want details of their condition to be shared, you must respect this (see our section on privacy.)



Keep in touch and up to date with the young person's well-being. This might be a phone call, email or even text message to a parent, as well as the regular meetings between the young person and their designated teacher. It's also important to remember that a lot of young people won't want you to talk about their conditions in the classroom or corridor etc., even if they are comfortable with the all members of staff knowing.



Remember to be flexible and aware that conditions and symptoms change, not only annually or monthly, but often from day to day. The most important thing you can do is show **compassion** and give support, even when you don't fully understand.

"The teacher in her class encouraged me to keep in touch and tell him how she was doing. His attitude was that he needed to know how she was so that he could be prepared in class"

Parent





Unpredictability of Illness

Flare-up

Noun

Plural noun: flare-ups

When the normal symptoms of an invisible illness become even worse, for a period of time.

They can happen at any time, anywhere, with or without warning.

Symptoms can vary, and each flare-up can present with features that were or were not present during the last flare-up.

The duration of symptoms can differ.

Over the course of a day, the young person can feel very different.

Symptoms can change and can seem unrelated to the condition.



No two people are the same, even if they have the same condition.

Be there to listen and try not to judge or assume.




Flexibility:

- ⚙️ Allow toilet breaks whenever needed
- ⚙️ Allow rest breaks without question
- ⚙️ Have measures in place for extensions on coursework, homework and exam sittings
- ⚙️ Individual plans should be developed for each young person, including support strategies and additional needs.

Empathy and respect:

 Trust

 Believe

 Listen

Be understanding:

- ⚙️ Some activities will need to be prioritised
- ⚙️ Goals might be different for young people with invisible illnesses. All are as individual as the person themselves
- ⚙️ All decisions should be shared, but ultimately led by the young person
- ⚙️ You may want to direct young people to relevant charities and organisations who could provide support to them.



Attendance

For a young person living with an invisible illness, school attendance can be a huge struggle.

Young people may regularly feel very unwell and fatigued. Flares and times of sickness will be unpredictable. Hospital stays and appointments can all bring huge additional pressures and seriously affect school attendance which can fluctuate and vary, often being as unpredictable the condition or disease itself.

Awards for attendance can be controversial. When given purely for attendance and not for attitude to learning this is unfair to a young person who will never be able to achieve full attendance levels.

Having to live with an invisible illness is already hugely unfair.

Attendance awards punish a young person for something entirely out of their control. There are many things to reward a young person for instead of this.



Top Tips



Communication between school departments about a young person's attendance is key to help everyone involved and avoid any extra stress for the young person and their family.



Flexibility and understanding will show a young person that they can have extra time and support to catch up on work they may have been forced to miss. Offering reduced timetables, phased returns, part time and online learning, could all be considered.



Attendance Awards should not be used. Awards can be given for effort and attitude and should be as individual as the young person themselves.



“In Year 11, I was not allowed to attend my Prom due to my attendance being too low over the year. I'd been really ill a lot of the time, and it was upsetting that I was punished for something I couldn't help”

Young Person



Exams


For young people living with invisible illnesses, exam time can be even more stressful than for other students.

Balancing exam preparation with the daily management of their invisible illnesses can be physically and mentally challenging, which may hinder them from achieving their potential.

Discuss with young people which arrangements will be of most use to them and contact the exam board as early as possible.

Special consideration could be an option if the young person is particularly unwell during the exam period.

Young people may want to consider changing their subject options if they are feeling overwhelmed. This decision needs to be led by the young person and their families, with support and guidance of staff.



“Allowing mid term exams to be done at home was helpful. Stopping and starting the clock at home, and giving them time to have breaks and stretch their legs”

Parent

Arrangements which can be made include:

- ⊗ **Extra time**
- ⊗ **A reader**
- ⊗ **Use of a laptop**
- ⊗ **Timed breaks**
- ⊗ **A scribe**
- ⊗ **Reducing the number of exams**
- ⊗ **Modified exam paper**
- ⊗ **Access to assistive technology**
- ⊗ **Completing exams orally**

Plan ahead:

- ⊗ Young people may need support in producing a revision timetable which accounts for their invisible illness.
- ⊗ Allow the young person to have a flexible timetable in the run up to exams, or even go on study leave early to so that they can revise while managing their invisible illness.
- ⊗ Offer extra sessions with teachers to catch up or cover subjects that have been missed or not understood.
- ⊗ Continue to offer support to the young person throughout the exam process and be aware that the level of support the young person needs may change throughout the exam period.
- ⊗ Check with the exam board what other access arrangements and reasonable adjustments are available.



Privacy

Sometimes young people may not want other people, including staff, to know about their illness, which can make it difficult for their class teachers to give the support needed.

A

ADVISE

Try to **advise** the young person that it will likely benefit them for their teachers to know about their situation but make sure not to dictate, should the young person still wish to keep things private.

S

SUGGEST

Suggest teachers are told from a practical point of view, but make it clear that they will not acknowledge to the young person that they know in class in front of others.

K

KNOW

Know any needs and integrate them into the normal running of the classroom. For example, if the young person needs to move fairly regularly in class, make sure they know that this is ok and that they will not be questioned.

What to do if a young person wants to keep their health private

- ⦿ It is vital that the young person's trust is kept, unless you believe this to be an essential safeguarding matter.
- ⦿ Have one teacher who they can arrange to meet regularly, at a time that suits them, to talk things through.

Early after a diagnosis, the young person may be reluctant to talk about it, but it is possible that further down the line, this may change.

- ⦿ The young person should be able to devise their own care plan.
- ⦿ Ask the young person to think about how they will express their needs to a teacher who doesn't know about their illness – if they need to leave the room or haven't completed homework for example.





Mental Health

It is highly likely that young people living with a chronic condition will experience mental **health** difficulties at some time. Research says that people with a chronic condition are ‘two to three times more likely to experience mental health problems than the general population.’

It is **important** to be **aware** of this when **supporting** a young person with an invisible illness.

More so than ever, young people suffer many pressures growing up that have a direct impact on their mental health. Living with an invisible illness can greatly increase this stress and anxiety. **Supporting** a young person’s mental health has to be a whole school, open and honest approach. Young people may feel vulnerable and their behaviour often masks what is going on, just as it sometimes does in adults too.

Young people with invisible illnesses have explained how sometimes they feel scared, stressed, angry, ashamed, jealous and guilty. The key to successful **support** is mutual **respect**, **confidentiality**, **trust** and being **aware** of the child’s safety at all times. Young people and parents must be involved and informed about interventions and support.

Naylor, Parsonage, McDaid, Knapp, Fossey, & Galea, (2012).
Long-Term Conditions and Mental Health: The Cost of Co-Morbidities

Disclaimer: Managing mental health is a very specialised area and on this page you will find suggestions to support a young person experiencing mental health difficulties along with links to professional organisations.



Behaviour

Look out for changes in behaviour such as tearfulness, being uncooperative, poor attendance, disruptive behaviour, and being withdrawn and distracted. Changes in behaviour can often mask many issues the young person is going through.



Relationships

If a young person feels part of a supportive and nurturing relationship with their teachers, they may feel more confident to talk about any worries and issues. It is essential that they are able to choose the member of staff they feel most confident to talk to.



Respect and Confidence

The young person needs to know they are respected and believed in order to feel safe enough to share concerns and ask for help and support. When good relationships are formed, young people feel confidence and a better level of security. They need to be able to trust their chosen adult to always have their best interests.



Tolerance and Attitude

A whole school culture of tolerance leads to a whole school understanding of mental health difficulties. Every member of staff plays their part in ensuring that every young person is accepted by their peers.



Communication

Young people need to feel they are being listened to, believed and trusted. Good communication between young people, teachers and parents is very important to supporting a young person's mental health. Young people and parents may want to decide when and where they talk to you and should not feel pressurised if they do not wish to. Transparent communication, when the young person is aware of conversations happening without them, makes sure the young person feels included and in control of their own health and wellbeing.

Communication with specific mental health professionals could be a key support for all involved. For more information go to:

<https://youngminds.org.uk/>

"We can't always choose what happens to us but whatever chooses us there is always a way to deal with it if we do it together"

Mum of a 9 year old boy





School Trips

Everyone with an invisible illness wants to feel the same as their peers and will look forward to a school trip with excitement.

Considerations may need to be taken into account.

This may include use of an accessible toilet, the suitability of transport, the length of the day, or the types of activities planned. As always, it will be **helpful** to **talk** to the young person as well a parent. They will be the expert of any additional need that will want extra **support** to ensure everyone has a good trip.



“Before the end of year trip, the teacher organising it phoned me to ask about anything my son might need. It was great to be able to chat in advance, so that he was able to fully enjoy the trip with his friends”

Parent



Case Study

Jack was diagnosed with a rare form of cancer, when he was just 3 years old. Here, his Mum Rachel shares part of their story.



*“When my son was **diagnosed with a rare cancer and a rare form of diabetes**, we had to very quickly learn a new language, a new way of living our lives and a new way of caring for him. He was absent from his nursery for a whole term and **on his return, the school were not very accommodating.***

*We were told that any medication would need to be administered by one of his parents and that **they could not ask a member of their staff team to help.** This made it tricky for us as we tried to resume normality with work etc. Luckily, I had an understanding employer and didn't work too far from the school.*

*The school were also asked to send a communication to all parents that there was a young person in school who had a **suppressed immune system and would be at risk of severe difficulties (and possible death)** if he was not treated quickly after contact with chicken pox and other infectious childhood*

illnesses. **Again the school senior management team were unhelpful.** They said they didn't want to cause 'hysteria' amongst other parents and would simply call us should they know about any chicken pox outbreaks. **This was a very scary and upsetting response for us.** Luckily, an incredible Macmillan nurse took over the communication with the school and explained under no uncertain terms why the school must send the letter.

We then moved house and area and Jack relapsed. **His new school could not have been more different,** despite being more than double the size of his first one.

The communication about chicken pox was shared quickly, we had **regular contact with teachers, they were happy to medicate him** with our written consent and he was even able to go away on a residential trip without us, which **allowed him a level of independence and normality that he had craved so much.**"



Rachel, Mum of 9 year old Jack



Getting Involved, Raising Awareness and Fundraising Ideas

It could be a good idea to show **support** for young people by getting involved with charities related to their condition. This can make the young person feel valued and that the school as a whole cares and wants to make a difference. The young person needn't be individually identified or involved, but the act will be appreciated by them and their families nonetheless.



A few fundraising ideas could be:

Non-uniform Day



Cake Sale & Table Top Sale



Quiz Night



Taking part in awareness weeks/months – many conditions/charities have a week or month dedicated to **raising awareness** (e.g.. October is Lupus Awareness Month)

- Another great way to get involved would be to incorporate education on invisible illnesses into **PSHE lessons**, so that other young people are made aware that some illnesses can't be seen. These sessions can be useful to inform about a variety of different illnesses, without needing to highlight specific young people in your school.



Support From Charities and Other Voluntary Organisations

Charities form the backbone of communities, often providing the support which public services, such as the health service, are unable to provide. There are lots of different charities in various areas, ranging from those focusing on a specific health condition, to ones specifically for young people, local causes, and everything in between.

Different charities offer a wide range of different services. These may include information resources, educational training, awareness activities, peer support opportunities, charitable grants, and much more! There's so much good happening in the world - the hardest part is making sure that everyone is aware of what is out there.

You can find all registered charities in the UK at the following websites:

The Charity Commission for England and Wales:

www.gov.uk/government/organisations/charity-commission

The Charity Commission for Northern Ireland:

www.charitycommissionni.org.uk

The Scottish Charity Regulator (OSCR):

www.oscr.org.uk

Contact Us

Web: www.raiise.co.uk

Email: info@raiise.co.uk



@raiiseuk



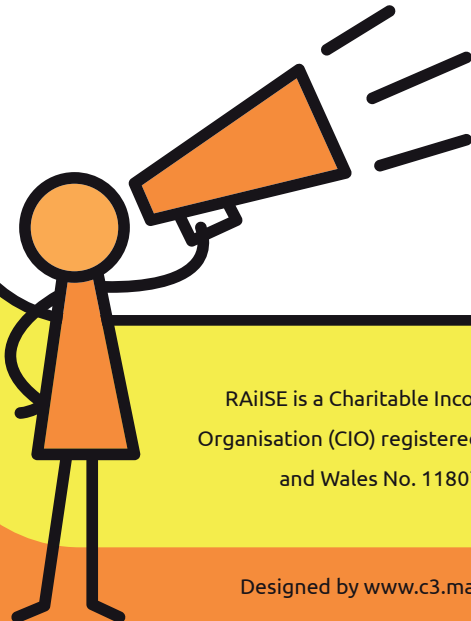
@raiiseuk



@raiiseuk



RAiISE



RAiISE is a Charitable Incorporated
Organisation (CIO) registered in England
and Wales No. 1180704

Designed by www.c3.marketing