



South Australian children and young people's experiences of living with chronic illness

COMMISSIONER
FOR CHILDREN AND
YOUNG PEOPLE

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The Commissioner for Children and Young People promotes and advocates for the rights, development and wellbeing of all children and young people in South Australia, with a special focus to engage with and listen to children who aren't usually heard. Helen Connolly became South Australia's first Commissioner for Children and Young People in April 2017.



THE ISSUE

Currently there is no systemic way to address the impact of chronic illnesses on South Australian children and young people. Without knowing the true extent of the problem, policymakers and support services are faced with considerable barriers to the planning and implementation of effective healthcare policies and services that can support children and young people living with chronic illness.

With the varied spectrum of symptoms and their severity, and no localised data showing the extent of the problem, it is difficult to ascertain what resources are needed and how they can best be deployed.

Children have the right to receive the best health care available and all children and young people should have information about how to stay healthy and safe across their communities. This right is enshrined in Article 24 of the United Nations Convention on the Rights of the Child (UNCRC). Further to this right, children have the right to an education. This right is enshrined in Article 28 of the UNCRC. With a lack of clear policy direction and support services available to children and young people suffering chronic illness, their ability to engage with their education is being severely impacted.

BACKGROUND

It is estimated that between 16 and 20 percent of children and young people in South Australia will suffer with a chronic illness at some point in their childhood. This figure is likely to be higher due to the underreporting of chronic illnesses. The lack of high-quality research and structural barriers that currently exist means this is impacting on children and young people's lives in significant ways, including an inability to engage fully with their education. Recent figures from a New South Wales-based study shows that chronic illness has a significant impact on educational attainment when children are hospitalised

more than once a year. The study found that an increase in hospital visits resulted in poor results across NAPLAN national education standards. This study does not account for teenagers completing their high school certificate, or children suffering undiagnosed chronic illnesses who are not hospitalised.

While national data provides us with some insight into the prevalence of chronic illness as it exists across a percentage of the population in each state, a lack of localised data dilutes the complex needs and experiences of South Australian children and young people so that supports are too generalised or lacking in detail.

Combined with a lack of high-quality research, the Commissioner for Children and Young People (CCYP) decided to complement the face to face consultations held in 2021 by undertaking a survey of children and young people living with chronic illness in South Australia. Conducted online from January to June 2022, survey responses were received from 95 South Australian young people who suffer from a broad range of chronic illnesses, often concurrently.

What was clear from the survey responses is that the impact and trajectory of each chronic illness varies greatly between each person. Some chronic illnesses are life-threatening, degenerative, relapsing, or require lifelong

management. Others are non-life threatening, invisible, and have symptoms that come and go. Many of the students surveyed suffered from mental health conditions alongside their chronic illness/es.

Respondents emphasised that there is no 'one size fits all' approach to supporting students with chronic illness, as the type, severity, and impact varies greatly between sufferers. Understanding the varied ways in which chronic illness impacts young people physically and mentally is vital if we are to develop ways to protect, promote, and support their overall health and wellbeing and importantly, support them to attain their education.

SNAPSHOT SUMMARY OF SURVEY RESULTS

Number of participants:
95

Age range:
13–21

Top 5 presenting illnesses:

- Asthma
- Endometriosis
- Chronic Fatigue Syndrome
- Type 1 and 2 Diabetes
- Arthritis

Type of school:

- 43% Public
- 25% Catholic
- 25% Independent
- 7% Other

The results of the chronic illness survey show that the South Australian education system, schools, and teachers, are not well equipped to support children and young people living with chronic illness. This is having a detrimental impact on the educational outcomes for those students, while also significantly impacting on their physical and mental health and wellbeing. The responses highlight a lack of understanding of chronic illnesses and how this is driving the exclusion and isolation of children and young people, at times putting their safety at risk.

In brief, there were:

- 73% of respondents who felt like their health wasn't being taken seriously
- 80% of respondents who missed out on activities
- 80% of respondents who missed out on school altogether
- 25% of respondents who were denied access to medication or other important health equipment or support while at school
- A majority of respondents felt pressure to continue doing work after telling a teacher they were feeling unwell.

- A majority of respondents felt pressure to continue doing physical activity after telling a teacher they were feeling unwell.
- More than half of respondents have been unable to negotiate deadlines, or make a plan that would allow them to catch up on assignments or school work.
- More than half the respondents had teachers who failed to follow up with them on an agreed support plan.

“ Just because it cannot be seen, [doesn't mean] that it isn't difficult for me. That just because I cannot do one activity or need to rest, it doesn't rule me out of everything. I need them to talk to me about my needs before making assumptions. I need to be given supports so that I can learn on a more equal footing to my peers.”

– Non-binary, 17

KEY MESSAGES

The quality of life, self-esteem and mental wellbeing of South Australian children and young people with chronic illnesses is being impacted by the lack of support they receive from schools, teachers, and the wider community. Being isolated from friends, unable to participate in sports, or take family holidays, is having a severe impact on their mental health and wellbeing over both the short and long term.

1

Children and young people with chronic illness need an array of resources to support them. These range from counselling services to accessing quiet facilities, from medical support to improved IT services.

2

Children and young people with chronic illness want their school and teachers to understand that being unable to concentrate, complete tasks, or attend lessons is a result of their illness, not a reflection of their attitude, intelligence, or work ethic.

Children and young people want 'support plans' that allow for flexible learning and assessment arrangements that enable them to better manage the competing demands of schoolwork and painful symptoms.

3

Children and young people want schools and teachers to be better able to deal with their chronic illness. For example, they want all teachers to undergo first aid training. They also want teachers to follow students' health action plans and know how to identify the signs of an impending medical emergency, so that they can respond accordingly and in a timely way before a crisis point.

4

Children and young people with chronic illness want help managing their workloads and deadlines, and they want to be supported by a flexible online and working from home arrangement that still embeds them in the classroom with their peers. This would ensure that those who need to work remotely, or who are hospitalised because of their illness, are effectively integrated into the classroom using teleconferencing technologies.

“I was only able to get minor accommodations even after fighting and getting lots of notes from doctors... After I was unable to physically come to school, teachers were more likely to just mark me as failed instead of giving me online versions of the assessments.” – Female, 18

IMPACTS

Chronic illness refers to health conditions that last for a long period of time with symptoms being different for different people. For sufferers of chronic illness, symptoms are often invisible and may vary in severity daily. This means that sufferers may not look 'sick' with their capacity for engaging with their studies varying alongside the changes to their symptoms.

Sufferers may also experience additional psychological and cognitive stresses as the impacts of chronic illness tend to reverberate through people's lives, impacting both their daily function and how they view themselves.

Suffering from chronic illness can be very isolating for many young people. Many of those who completed the survey reported feeling embarrassed and misunderstood. They were frustrated by their peers' judgemental attitudes citing examples such as needing to sit out of physical activity or be granted an extension on an assignment being seen as some kind of "special treatment" or a form of favouritism. Others felt very lonely and often invisible due to their chronic illness, making it hard for them to attend social events, play or hang out with peers at lunch time, or develop and maintain their social relationships over the short or long term.

“...The loss is not just education; it's being isolated from very important stages of learning relationships. You quickly become invisible and things in common fall away. The brief time that may be spent with peers, perhaps online, is a snippet of the day. Appearing well for a short time does not show the collapse afterwards, the complete loss of function. Young people need help to understand the gravity of the situation.” – Male, 16

Inclusion and involvement

Children and young people suffering with a chronic illness are not lazy or irresponsible – often they are struggling with managing daily tasks and schoolwork alongside management of their pain. Some respondents expressed feeling embarrassed when they needed to make requests for extra time or felt as if their needs were not being taken seriously. For some respondents whose chronic illness is ‘invisible’ they wanted to emphasise that having symptoms that flare and fade day to day, does not mean their condition isn't real. Students wished teachers understood this and were empathetic, flexible, and much more accommodating to their changing health situation.

Often too they said that online learning options do not fully include students in the classroom environment – especially when the majority are able to sit in a class. Only spending a brief snippet of time with their peers in online classes isolates students from normal social experiences. Outside of school, students reported that their symptoms were often too severe to attend social events with their peers and that unsurprisingly, this made them feel even more isolated.

Many respondents said they had been met with scepticism. They had experienced teachers and peers who said they were faking their illness, or seeking attention, or special treatment. This further drives the cycles of shame, embarrassment, and isolation that many of the respondents said they experienced.

Such attitudes and lack of empathy and understanding further isolate sufferers of chronic illness from both their peers and their education. Some even reported having

experienced bullying and social isolation from their peers and alarmingly from their teachers. Some students were teased for their symptoms while others were excluded and ridiculed for their appearance. Some of their peers feared their chronic illnesses were contagious. Often these students said they felt as though their teachers and peers did not believe what they were experiencing, or were prone to pressuring them to participate beyond their capacity.

Many of the respondents missed out on school because of their symptoms. Often, they struggled to catch up on their school work or were unable to negotiate extensions or accommodations for the work assessment. They encountered problems trying to make alternative learning arrangements with individual teachers, as well as with their school and the SACE board.

Students not only wanted flexible arrangements to accommodate their chronic illness, they also wanted alternative pathways into university or TAFE to be better explained and supported by their teachers and school.

For some of the respondents, their illness was a source of shame and embarrassment. They felt embarrassed about needing to ask for extensions or special accommodation for their schoolwork and at times chose to push themselves beyond the threshold of their pain or symptom tolerance to avoid having to ask, with this invariably leading to longer periods of sickness or absences from school and classes.

In some cases, rather than their chronic illness being treated as a genuine health disruption to their education their cases were treated as absenteeism or school avoidance, causing students to feel unsupported and punished for having a chronic illness/es.

“Punishing the student won't make it go away, it will make the person avoid attempts to manage conditions, resulting in what seems like an increase in symptoms or time off. It is not convenient. Procrastinating management methods can lead to hospital trips. Do not gang up on the student in front of peers. Do not remove students from peers due to chronic illness or conditions they have.” – Non-binary, 20

Belonging and wellbeing

Diagnosis with a chronic illness can be a lifechanging event that can cause massive social upheaval and disrupt the trajectory of young sufferers' lives. Research indicates that 28% of people diagnosed with a chronic physical illness also have a mental health condition to manage simultaneously.

Frequent and prolonged absences from school have a considerable impact on children and young people's social lives. In addition to missing school-run activities with their peers due to their chronic illness, some students struggle to maintain their social relationships with peers.

Many students suffering with a chronic illness said they experienced exclusion and isolation from school-based activities. Depending on the severity of their illness, these children and young people often missed out on curricular sports lessons, sports days, fun days, and school excursions, as well as extracurricular activities.

An apparent lack of training and preparedness to deal with medical emergencies made students who are suffering with chronic illness/es nervous to attend either school or social events in case their teachers or the volunteers attending were unable to help them in the event of an emergency.

Add to this the fact that children and young people suffering from chronic illness often experience depression and anxiety due to their pain levels it's easy to see how severe and far reaching the impact of their condition can be.

Often chronic illnesses also impact how the sufferer views themselves. Attitudes toward chronic illness in schools, from both teachers and peers, can be isolating for students. There is considerable need for psychological support to be made available for students who are suffering from both chronic physical and mental health conditions while trying to engage with their education at school.

“Despite the basic care the school offered such as offering extended due dates, and trying to get me to a counsellor, or having an SSO in the class, no one understood I was grieving sight loss and battling pain and anxiety from flares since my first diagnosis in 2010 up to graduating in 2021.

I felt like I couldn't talk to anybody because no one understands this matter and everyone was thinking about the tasks and assignments and due dates they were given.” – Female, 18

Some sufferers are grieving the loss of a “normal life”, needing to make significant adjustments to accommodate their health and coming to terms with new limitations alongside experiencing the full-time demands of managing a chronic illness and schooling. Respondents wanted their teachers and peers to know that some chronic illnesses require 24/7 management. A lack of understanding of the nature of chronic illnesses often makes sufferers feel misunderstood or isolated. These educational, extra-curricular and social challenges are all additional stressors for children and young people suffering chronic illnesses.

Being understood and supported

At the heart of these issues, is the lack of understanding and awareness from schools, teachers and peers in relation to the severe and far-reaching impacts chronic illness has on children and young people who are sufferers. The variance in symptoms and severity of a chronic illness can change day-to-day and from person-to-person. Some sufferers experience moderate symptoms which they are able to self-manage while others experience debilitating and painful symptoms that require hospital visits.

“I struggle with a physical disease but, it's not just physical. It has had the biggest impact not only on my development as a human but also with my mental health. I wish teachers understood the seriousness of this. I feel like no one understands my every day struggles, purely due to lack of knowledge and understanding.”
– Female, 17

Students living with chronic illnesses want their teachers and peers to have a greater awareness of the shifting nature of their illness and to show understanding around the various ways it impacts on their schoolwork and daily lives. The majority of respondents surveyed reported that they felt unsupported, 'invisibilised' and generally misunderstood by many of their teachers and peers who they said in some instances displayed pervasive and discriminatory attitudes toward invisible and varying symptoms of their chronic illness.

“ Most teachers do not understand the impacts having scoliosis can cause. I often miss school for appointments or can't complete work because I'm in a severe amount of pain... yet the teacher does not allow me to make changes to help prevent this. I get told off for wearing a different uniform...despite having a doctor's note. Most teachers will say it's just an excuse to wear a different uniform or get assignment extensions, which is not true at all.” – Female, 14

NEXT STEPS

There are many misconceptions surrounding chronic illness. Students suffering with chronic illness/es are frequently met with a lack of understanding and empathy from their teachers and peers. Often, they are being perceived as either lazy, faking their illness, or seeking special treatment. These attitudes make students feel embarrassed about asking for help. It reduces confidence in their school or teachers to accommodate their situation or needs. Others expressed having experienced animosity from their peers, who they said felt that the special treatment or accommodations being made for chronically ill students seemed to be a form of favouritism and special treatment and that this also prevented them from asking for any support.

There appears to be an inextricable link between prejudiced beliefs and the lack of support, resources, and training currently being made available to students who are suffering with chronic illness/es. Some respondents spoke about the lack of focus on up to date first aid treatment for teachers and school staff. They also said that the knowledge around the biometrics of their conditions showed no comprehension from teachers or schools particularly in regard to the combined psychological and physiological responses students have when they suffer an incident or 'episode' that may take different timeframes to "get over".

As a result of such a severe lack of understanding, there is a distinct lack of practical support being made available to children and young people suffering from a chronic

illness, as they endeavour to exercise their right to access their education.

There is no 'one size fits all' approach that can be taken to providing support for students with chronic illness. Due to the varied severity of symptoms each response must be tailored to the individual's situation and circumstances. Not surprisingly it is provision of this tailored approach that is one of the key challenges schools and teachers face, when deciding how best to support students with chronic illness attending their school. They must also do this in the absence of a policy mechanism or any guidelines provided at the state or national level, as currently none exist. Open communication between students, their parents or caregivers, teachers, and the school, is crucial to ensuring the right support is given. Most importantly, the support needs to be co-designed with direct input from the student themselves with regular reviews put in place to address what may have changed and adjust what isn't working.

“ As long as teachers continue to take their information from the charts and don't listen to what children are saying, respondents felt it was unlikely to change and that they would remain misunderstood and unsupported.” – Helen Connolly, Commissioner for Children and Young People

RECOMMENDATIONS

Students with chronic illness/es must feel safe and supported at school. This means policy, program, and research actions need to be taken to make this happen. Teachers need to be supported and trained to deal with medical emergencies that may occur to their students and in their classrooms or on the school ground. They must also be able to implement appropriate support and action plans for their chronically ill students. To achieve this the following recommendations have been proposed:

1

Respondents expressed a need for their teachers, peers, and schools to be better trained to deal with chronic illnesses and related emergencies. Young people were concerned that staff don't know the signs of a potential medical emergency, or how to appropriately treat a student who has one. This makes all students with chronic illness anxious about attending school and in many cases leads them to actively avoid school.

2

Students suffering with chronic illnesses need quiet rooms and spaces where they can work separately from other students while experiencing symptoms. Spaces like this are especially important to students whose chronic illness may put them at a greater risk of adverse outcomes from other viral or contagious illnesses that are frequently circulating amongst students such as COVID-19 or influenza.

3

Better study from home and online schooling options for children and young people suffering from chronic illnesses need to be put in place so that they are better supported and included in their education and school. COVID-19 has seen an increase in the use and familiarity with online and integrated learning technologies, including greater flexibility with learning modes. This is proof that flexibility and tailored accommodations are possible for students living with chronic illness and can include provisions for those who have complex needs.

4

Flexibility with community learning and online VET courses highlighting alternative pathways to university that go beyond ATAR are necessary. This would involve also ensuring students with chronic illness/es are offered more flexible forms of assessment (eg more assignments and essays) over standardised testing.

5

Greater awareness and understanding among teachers and peers of the impacts of chronic illnesses on the lives of children and young people are key. This would include knowledge of the impact chronic illnesses have on the capacity for children and young people to develop friendships and maintain social relationships, including their importance in increasing their involvement in daily life outside of school.

“ There is no one size fits all approach to supporting students with chronic illness to access their education. Tailoring approaches that are co-designed with the child or young person suffering with chronic illness/es are much more likely to work. Open communication between teachers, students and parents is crucial to getting the balance right.” – Helen Connolly, Commissioner for Children and Young People