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Challenging school experiences of unavoidable absence and return for young people with chronic health conditions in English secondary schools: a qualitative, multi-informant study

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Introduction: School absences rates in England have remained high since the COVID-19 pandemic and reducing absence is a policy priority. Evidence shows that young people with chronic health conditions have higher school absence and worse educational outcomes. We examined the perspectives of young people, caregivers and school staff on school absence and return for English secondary school pupils with chronic health conditions.

Methods: We recruited participants through professional networks and health/education organizations, emailing a link to an online qualitative survey. Data analysis was thematic.

Results: We received survey responses from 12 young people, 33 caregivers, and 18 school staff. Across the young people and caregiver sample ($n = 45$), two-thirds reported that they or their child had 2 + conditions; 49 different conditions were reported. The nature of absence and its predictability varied. While absent, participants reported that young people fell behind with schoolwork and were isolated from their peers; school support was described as patchy or non-existent. On return to school, young people's health affected their performance in class and exams and inclusion with peers. Attending school, and its associated stresses, could also negatively impact on young people's conditions. Young people and caregivers reported that pupils needed caring, reassuring behavior from staff and support to catch-up and succeed academically. Gaps were identified in staff knowledge.

Discussion: Policy and practice should focus on mitigating the impact of unavoidable health-related absence.

KEYWORDS

school absence, school refusal, child health, adolescent health, inclusive education

Introduction

The UK government has been concerned about elevated school absence rates in England since the COVID-19 pandemic (Children's Commissioner, 2023; Department for Education, 2024b; UK Parliament, 2023). In the autumn term 2023/24 in England, around a fifth (19.2%) of children and YP were persistently absent, missing at least 4 weeks in an academic year (Department for Education, 2024c). School absence has consistently been associated with lower educational attainment (Ansari and Gottfried, 2021; Klein et al., 2022), and a heightened risk of other negative outcomes in later life such as absence from the labor market (Dräger et al., 2024) and involvement in crime (Rocque et al., 2017). Absence is socially patterned, with higher absence for children eligible for free school meals and children with additional educational and/or health needs (Hunt et al., 2025; Klein et al., 2020; Long and Roberts, 2025).

It is estimated at least 12.5% of children have a chronic health condition from ages 5 to 11, and 18.9% to age 16 (Jay et al., 2025). Chronic health conditions are enduring physical, physiological, neurological and/or mental health problems that impact on children's daily activities (Brooks et al., 2020; Champaloux and Young, 2015; Lum et al., 2017). National surveys indicate around 14.8% of children and young people have comorbid long-term physical and mental health conditions (Panagi et al., 2024). In England, around one in four (25.9%) young people with chronic health conditions have persistent school absence compared to one in seven (14.7%) of their peers at age 15/16, and persistent absence is especially high among those with mental health presentations (Jay et al., 2025). Poor mental health has been associated with "emotionally based school avoidance" (also known as school refusal) whereby a young person associates attending school with emotional distress (Egger et al., 2003; Elliott and Place, 2019; Tekin and Aydın, 2022), and some have proposed that this type of school avoidance has been exacerbated by the pandemic (Lester and Michelson, 2024).

Absence for children with chronic health conditions can directly result from medical appointments or hospitalisations, but it can also be related to: a condition's symptoms (e.g., managing fatigue and pain); motivations to avoid school (e.g., due to anxiety, to avoid bullying); the social determinants of health (e.g., housing instability affecting both health and school attendance); and unmet needs in the school environment (Allison et al., 2019; Dannow et al., 2020; Dyson et al., 2010; Finning et al., 2019; Hopwood et al., 2024; Spencer et al., 2023b). Although a political focus on school absence has been justified by data showing that absence is linked to attainment (General Certificates of Secondary Education, Department for Education, 2016), there is limited evidence that absence explains the association between chronic health conditions and lower attainment (Beynon and Thomson, 2022; Jay et al., 2023).

In England, schools have a duty to support pupils with any medical condition, including those with chronic health conditions, ensuring that they are healthy and safe in school, absences are effectively managed, and pupils receive appropriate support to participate in education (Children and Families Act 2014 c.6 Part 5, 2014; Equality Act 2010 c.15 Part 6, 2024; Department for Education, 2015). Schools do not have to wait for a formal diagnosis before providing support to pupils (Department for Education, 2015). However, evidence suggests that without medical diagnosis or visible signs of ill health, school personnel may question the illness's

legitimacy (Dyson et al., 2010; Herlitz et al., 2025; Spencer et al., 2023a; Winger et al., 2014). Young people, carers, and teachers themselves have reported concerns about educators' lack of knowledge and training about pupil's health needs (Bowtell et al., 2018; Dyson et al., 2010; Hinton and Kirk, 2015).

In qualitative studies, young people with chronic health conditions and caregivers have reported they have felt a lack of school belonging and social isolation and that staff did not listen to them when they explained their needs and respond appropriately (Bowtell et al., 2018; Dannow et al., 2020; Herlitz et al., 2025; Spencer et al., 2023a). Young people and caregivers have highlighted that school attendance systems, including attendance targets and incentives, unfairly depreciated and punished vulnerable pupils who could not avoid health-related absences, negatively affecting their self-esteem and sense of school support and inclusion (Herlitz et al., 2025; Hopwood et al., 2024).

There are few primary studies that examine commonalities in school experiences among young people with different chronic health conditions, triangulating multiple informants' perspectives (Spencer et al., 2023b). Building on our study of accessing health and wellbeing support in secondary schools (Herlitz et al., 2025), we wanted to understand young people with chronic health conditions' experiences of health-related absences and return to school. We asked: what are the views and experiences of young people, caregivers, and school staff of school absence and return for young people with chronic health conditions?

Materials and methods

Design

We used a qualitative survey design (Braun et al., 2021) to explore school experiences for YP with chronic health conditions, creating two online surveys: one for young people, parents/caregivers, and one for school staff (see registered protocol <https://osf.io/b6ysr>). The study was approved by the UCL Research Ethics Committee (REC reference: 17893/005).

This study was part of a larger research project which used administrative health and education data to estimate the prevalence of chronic health conditions in the English school population and the association between school absences and health (Jay et al., 2025; Jay et al., 2023, 2024). This study was designed to complement the quantitative analysis to better understand how long-term health problems contributed to absence, impacted on learning and attainment, and how school experiences could impact on children's health.

Consultation with young people and parents

We consulted with the National Children's Bureau's (NCB) Family Research Advisory Group (FRAG), a group of parents of YP with chronic health conditions, in May 2022 about their research priorities and perspectives on the relationship between chronic health conditions and school absence. Their feedback informed our decision to adopt an inclusive definition of chronic health conditions, and our

survey questions. Through the Anna Freud mental health charity, we invited a young person with chronic health problems to review our survey questions to make sure they were clear and understandable. We sense-checked and discussed the emerging findings with the NCB's Young Research Advisors' group and the FRAG in June and September 2023, respectively.

Sampling and recruitment

Young people and caregivers were eligible to participate if a young person reported that they had one or more conditions (physical or mental) which required healthcare input for 1 year or more, regardless of whether a young person had been given a diagnosis. [Table 1](#) presents participants' eligibility criteria. We included young people aged 16+ years only so that they could reflect on their full school experience and give informed consent. We aimed to recruit 30 young people and 30 caregivers with a wide range of conditions to achieve a "medium-size" qualitative sample ([Braun et al., 2021](#)). We aimed to recruit 35 secondary school staff with a diversity of roles.

We used a convenience sample for both surveys. We recruited young people and caregivers by advertising the study through relevant networks and organizations related to health, mental health and education and social media [Twitter (now "X"), Facebook] (see [Supplementary File 1](#)). We recruited school staff through the Health Conditions in Schools Alliance, Anna Freud Schools in Mind network, UCL Great Ormond Street Institute of Child Health, the National Education Union (NEU), the UCL Institute of Education secondary school student teachers' network and our professional networks.

Data collection

We used Qualtrics (Qualtrics, Provo, UT) as the survey platform. Interested individuals followed the link to the survey landing page, which provided a study overview and a link to the information sheet. The consent form followed and if participants responded "yes" to all questions, they could progress to start the survey. Young people and

caregivers were also given the option to contact the research team if they preferred to take part by email or Whatsapp voice messages, however, no requests were received.

The young people and caregiver survey was live from 7th November 2022 to 31st January 2023. It filtered the questions based on whether participants reported they were a young person or caregiver. Both young people and caregivers were asked to describe the conditions they or their child had (free text), followed by open-ended questions about their school experiences. Participants were also asked to complete demographic questions (see [Supplementary File 2](#)). At the end of the survey, participants could enter a prize draw for a £50 voucher. On average, young people took 24 min and caregivers took 38 min to complete the survey.

The school staff survey was live from 30th January to 5th May 2023 to adapt the questions based on emerging findings from the young people and caregiver survey. The survey asked several open-ended questions about how pupils with chronic health conditions were supported (see [Supplementary File 2](#)). Participants were also asked to complete demographic questions, questions about their role and teaching experience. At the end of the survey, participants could enter a prize draw for a £50 voucher. We piloted the school staff survey with two teachers to ensure the questions were understandable. On average, school staff survey took 23 min to complete.

Data analysis

Demographic characteristics were analysed descriptively. There was a notably high degree of missingness for gender among young people and caregivers, with 25% missing for young people and 61% missing for caregivers, though no missingness for school staff. We used an open-ended text response for gender to encourage inclusivity but, unexpectedly, this may have been off-putting for some participants.

Open-ended survey answers were initially analysed using semantic thematic analysis ([Miles and Huberman, 1994](#)), using NVivo 12 software ([Lumivero, 2017](#)). While most participants wrote a short paragraph for each question, text responses varied in length from just a few words to over 1,500 words. One researcher (LH) read and re-read answers and carried out line-by-line inductive coding. Emerging themes focused on: school life moving forward in young people's absence; managing illness and isolation; and emotional, academic and social support. However, the format of the fragmented survey answers meant it was difficult to get a holistic view of participants' experiences as well as cross-check their responses to specific questions by participants' demographics and descriptions of their condition.

Following consultation with young people and parents, which highlighted the specificity of each young people's condition and learning needs and the lack of suitable educational support, LH conducted framework analysis ([Gale et al., 2013](#)) to systematically re-check the codes and themes. A structured template in Microsoft Excel was used to examine the data for each participant, including their demographic variables and description of the young person's condition (for young people and caregiver respondents), against each theme with each row an individual participant's response and each

TABLE 1 Participant inclusion criteria.

Participant	Inclusion criteria
Young person	<ul style="list-style-type: none"> Aged 16–25 years. Had one or more chronic health condition(s) while at secondary school. Attended a mainstream secondary school in England.
Caregivers	<ul style="list-style-type: none"> Cared for a YP aged 11–25 years. YP had one or more chronic health condition(s) while at secondary school. YP attended a mainstream secondary school in England.
School staff	<ul style="list-style-type: none"> Worked in a mainstream secondary school in England. Had one of the following roles: <ul style="list-style-type: none"> Teaching or supporting students in the classroom A school leader with responsibility for school policies Educational psychologist

column a code, with related codes organized into neighboring columns to create themes. LH separated out experiences of absence from experiences of returning to school, and explored positive, negative, and desired experiences of staff support.

To explore whether young people and caregivers' responses notably differed according to their reports of whether the young person had a mental health condition or not, we coded anxiety, eating disorders, depression, obsessive compulsive disorder, developmental trauma, and post-traumatic stress disorder as mental health conditions. We compared responses for each theme according to this code classification and report any salient differences.

Reflexivity statement

The research team are part of a policy research unit; the study's design and methods were chosen to provide timely, policy-relevant evidence. At the time of the study, the year following the pandemic (2022), education policies focused heavily on improving school attendance as a means to improve children's welfare and attainment. The bulk of the data collection and analysis was led by two female researchers (LH and CP) highly experienced in qualitative data collection and analysis, and LH has led previous studies focused on school settings. Neither researcher has lived experienced of raising or teaching a child with chronic health conditions. The wider study team comprised of researchers with expertise in population health and children's mental health.

Results

We present the participants' characteristics followed by the key themes we constructed from the data. In quotes where young people have multiple conditions, to preserve anonymity, we have named the first condition and indicated "other conditions."

Sample characteristics

Twelve young people completed the survey (19 young people completed the consent form), and 33 caregivers completed the survey (46 completed the consent form). Young people and caregivers were from diverse locations across England (see [Table 2](#) for young people and caregiver characteristics). Two-thirds of both young people and caregivers reported that they or their child had more than one condition. Forty-nine different conditions were reported across the young people and caregiver sample ($N = 45$); most often reported were: anxiety ($n = 13$, 29%), myalgic encephalomyelitis (ME)/chronic fatigue syndrome (CFS) ($n = 9$, 20%), autism ($n = 7$, 16%) and asthma ($n = 7$, 16%) (see [Supplementary File 3](#)). Eighteen school staff completed the survey (35 completed the consent form). Just over half were school leaders and a third were staff teaching or supporting students. Most had been teaching for 10+ years (see [Table 3](#) for staff characteristics).

Views and experiences of school absence and return, and staff support

We constructed three overarching themes from participants' responses: "Variation in types of absence and common experiences of falling behind"; "Experiences of learning and integration with peers on return to school"; and "The vital importance of staff support for young people with chronic health conditions" (see [Figure 1](#)).

Theme 1. Variation in types of absence and common experiences of falling behind: "I could never have 100% attendance"

We constructed two sub-themes related to young people's experiences of being absent and its impact on their studying and peer relationships: "Different types of absence," and "Falling behind with learning and socializing."

Different types of absence

Most participants reported that young people with chronic health conditions were frequently absent from school due to fatigue or other symptoms, or to attend medical appointments in school time. The nature of absence that they reported varied, absence could present as: large blocks of time off, predictable frequent absence (e.g., for medical appointments), unpredictable frequent absence (e.g., episodes of ill health), cycles of absence (e.g., activity followed by burnout and respite), and frequent late attendance (see [Table 4](#)). Two young people with physical conditions noted that when they knew about hospital appointments in advance (usually longer absences), they could organize work to complete remotely, but they were not able to do this when appointments came at short notice. One staff member highlighted that pre-diagnosis stages could be particularly disruptive to attendance due to ongoing tests/appointments and ill health.

Falling behind with learning and socializing

Caregivers, young people and staff reported young people fell behind with schoolwork while absent and one teacher and caregiver noted that falling behind could be particularly detrimental in "building block" subjects like maths, where progression relies on mastery of previous concepts. A caregiver and some young people reported that they had missed exams due flare-ups or being hospitalized for poor health, which set them back significantly in their education, for example, having to repeat a school year.

Many caregivers and a young person reported that absence was accompanied by an array of negative emotions, with young people feeling guilty, anxious, stressed, or depressed for being unable to attend, and scared about being behind in their education, with "a mountain of work" in front of them (Caregiver_P). This applied to participants' accounts of all young people, regardless of whether or not they had reported a mental health condition. Multiple informants noted that as well as falling behind in their studies, absence isolated

TABLE 2 Young people and caregiver demographic characteristics.

Demographic characteristics	Demographics sub-categories	Young people N (%)	Caregiver N (%)
Gender	Female	6 (75)	12 (92)
	Male	2 (25)	1 (8)
	No response	4 (33)	20 (61)
	Total	12 (100)	33 (100)
Age	16–18 years	5 (42)	n/a
	19–25 years	7 (58)	n/a
	26–35 years	n/a	0 (0)
	36–45 years	n/a	7 (22)
	46–55 years	n/a	20 (63)
	56–65 years	n/a	5 (16)
	No response	n/a	1 (3)
	Total	12 (100)	33 (100)
Ethnicity	White British	8 (67)	24 (73)
	White European or Other	1 (8)	4 (12)
	Black British, Caribbean, or African	0 (0)	2 (6)
	Asian or Asian British	2 (17)	0 (0)
	Mixed or multiple ethnic group	0 (0)	0 (0)
	Other ethnic group	0 (0)	1 (3)
	Prefer not to say	1 (8)	2 (6)
	Total	12 (100)	33 (100)
Location	North England	1 (8)	6 (19)
	Yorkshire and the Humber	4 (33)	6 (19)
	Midlands	1 (8)	4 (13)
	East of England	1 (8)	2 (6)
	London	1 (8)	7 (22)
	South England	4 (33)	7 (22)
	No response	n/a	1 (3)
	Total	12 (100)	33 (100)
Presence of individual health plan	Yes	9 (82)	17 (52)
	No	2 (18)	16 (48)
	No response	1 (8)	n/a
	Total	12 (100)	33 (100)
Presence of special educational	Yes	7 (58)	18 (52)
	No	5 (42)	16 (48)
	No response	n/a	1 (3)
	Total	12 (100)	33 (100)
Number of conditions	Single condition	4 (33)	11 (33)
	Two conditions	4 (33)	9 (27)
	Three conditions	2 (17)	5 (15)
	Four or more conditions	2 (17)	8 (24)
	Total	12 (100)	33 (100)
Mental health condition	No mental health condition reported	8 (67)	21 (64)
	Mental health condition(s) only	2 (17)	2 (6)
	Mental health and other condition(s)	2 (17)	10 (30)
	Total	12 (100)	33 (100)

TABLE 3 School staff demographic characteristics.

Demographic characteristics	Demographics sub-categories	School staff N (%)
Gender	Female	16 (89)
	Male	2 (11)
	Total	18 (100)
Age	19–25 years	1 (6)
	26 to 35 years	4 (22)
	36 to 45 years	5 (28)
	46–55 years	6 (33)
	56–65 years	2 (11)
	Total	18 (100)
Ethnicity	White British	15 (83)
	White European or Other	1 (6)
	Black British, Caribbean, or African	0 (0)
	Asian or Asian British	1 (6)
	Mixed or multiple ethnic group	0 (0)
	Other ethnic group	0 (0)
	Prefer not to say	0 (0)
	Total	18 (100)
Location	North England	0 (0)
	Yorkshire and the Humber	0 (0)
	Midlands	6 (33)
	East of England	3 (17)
	London	0 (0)
	South England	9 (50)
	Total	18 (100)
Role in school	Staff teaching or supporting students	6 (33)
	Staff with a leadership role	10 (56)
	Educational psychologist	2 (11)
	Total	18 (100)
Length of time teaching	Under 3 years	0 (0)
	3–5 years	2 (11)
	6–9 years	4 (22)
	10 years or more	12 (67)
	Total	18 (100)
Size of school population	Less than 500 students	5 (29)
	500–899 students	2 (12)
	900–1,199 students	3 (18)
	1,200 or more students	7 (41)
	No response	1 (6)
	Total	18 (100)

the young people from their peers, negatively affecting their social life and confidence:

“Lessons are something that can be done at home in a more accessible way, but the social interaction is much more difficult to replicate.” Young person with ME/CFS and another condition.

A few caregivers said that no schoolwork was sent home when their child was absent and several reported that government policy was not followed on providing alternative education arrangements when their child missed 15+ school days due to illness. Several staff and caregivers recognised that families have mixed success with remote learning, for example, parents with English as an additional language might not be able to assist their child, or pupils with additional learning needs:

“Students with complex learning needs and/or neurological conditions such as autism in addition to health needs can also be more difficult to support effectively due to factors such as specialist resources or teaching strategies being required that are not easily replicated at home.” Staff-B.

In contrast, some participants gave examples of successful online teaching experiences, and a few caregivers that had not been offered access to online lessons thought their child would have benefited from them.

Theme 2. Managing learning, friendships and continuing ill health after absences: “he struggled with work, friends, planning and managing the school day”

When young people returned to school after absences for ill health, participants reported significant challenges in catching up and progressing in learning and connecting with their peers. We constructed two sub-themes on this subject: “The interaction of health conditions on learning and exams,” and “The impact of conditions on peer integration and wellbeing.”

The interaction of health conditions with learning and exams

Young people and caregivers described the impact of health conditions on young people’s school performance. Many young people and caregivers described how children felt tired and drained from their condition(s), affecting their ability to engage in lessons, concentrate, move around the school, and take part in physical education/activities. Young people and caregivers reported their or their child’s condition could also affect their ability to concentrate and process information, for example, due to brain fog or exhaustion. High anxiety was particularly mentioned by caregivers and young people who had reported a mental health condition. They described how it could affect a child’s ability to stay in class or manage the school day as they experienced physical symptoms (e.g., difficulty breathing, nausea). Multiple informants reported that anxiety, fatigue, discomfort, or pain that coincided with exams, could affect young people’s performance and subsequent results:

“Anxiety, unpredictability of how the illness will develop, loss of motivation, added stress, exam stress (having to perform at a certain moment when pain levels might be high), angry at her body, it feels

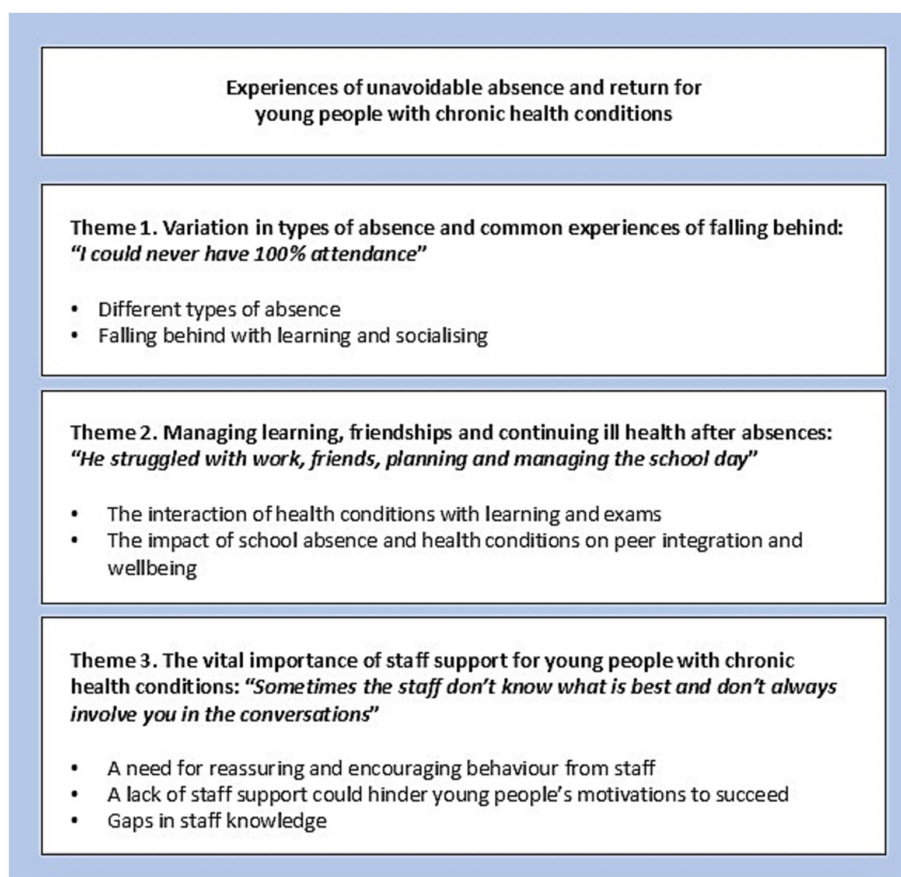


FIGURE 1
Key themes.

unfair to know that you could do much better.” Caregiver-P of YP with severe headaches and other conditions.

Caregivers and one young person noted that children expended considerable mental and physical effort on appearing to be a “normal” pupil. Unpredictable changes, such as sudden increases in pain, could be difficult to manage, and be poorly understood by staff. Attending school, and its associated stresses, could also negatively impact on young people’s conditions. One caregiver noted the link between their child’s level of pain and school stress, and several caregivers, a staff member, and a young person reported that physical and mental exertions at school had led to burn out/exhaustion:

“We were always pushing for full time school which in hindsight was always unrealistic. We never gave her enough time to consolidate her attendance and cope with the level she was at before pushing for another morning or another day and when we went a step too far her health tumbled and we were back to square one.” Caregiver-AB of YP with hemiplegia and another condition.

“When recovering from major back surgery, one of my students often stayed home because teachers did not understand the impact of the pain she was experiencing. She tired very quickly and her energy levels were very different from day-to-day and throughout

the day. If she came into school, she was expected to put in a full day and this was often unmanageable for her. She did not like to ask for concessions and, because she had missed so much school, the school was reluctant to let her go home once she had arrived. This meant she often missed an entire day when she might have been able to manage a lesson or two.” Staff-J.

The impact of school absence and health conditions on peer integration and wellbeing

Many participants highlighted that absence from school isolated the young person from their peers, while at school, “*life [is] going on without you*” (Young person_D). Several caregivers and one young person described how children’s condition(s) also constrained their ability to take part in lunchtime and after-school activities like sports clubs, as well as school trips and residential, due to fatigue or needing medication to be administered:

“Very hard to maintain friendships if one does not have the energy to either be in school or do any of the things that his peers would like to do (play sport, walk to the shops etc.)” Caregiver-Q of YP with ME/CFS.

TABLE 4 Examples of different types of absence.

Type of absence	Supporting quotes
Large blocks of time off	<ul style="list-style-type: none"> “Could hardly attend school post diagnosis. Lost most of his school in years 8 and 9. Only 6% attendance in year 10.” Caregiver-Q of YP with ME/CFS. “YP had a heart attack and was hospitalized for several months.” Staff-B
Predictable frequent absence	<ul style="list-style-type: none"> “Throughout my education... I was in and out of hospital so much... I would even refer to it as my second home... I could never have 100% attendance.” YP-H with prosthetic eye and other conditions.
Unpredictable frequent absence	<ul style="list-style-type: none"> “My daughter missed days of school and was often collected at lunchtime in tears, unable to complete the day.” Caregiver-AE of YP with asthma and other conditions.
Cycles of absence	<ul style="list-style-type: none"> “Often she would improve over the summer, get back to school in September and then by the end of October/November she would deteriorate and be off school again.” Caregiver-AB of YP with hemiplegia and another condition.
Frequent late attendance	<ul style="list-style-type: none"> “Always late to school most of the time, suffers from a lot of fatigue.” Caregiver-Y of YP with sickle cell anaemia and another condition.

Many caregivers and most young people reported that their friendships and peer relationships were hugely important and were affected by their condition(s). Some young people gave examples of friends and peers being supportive, giving practical support or showing kindness, and some caregivers and young people reported that they had managed to maintain friendships outside of school through other personal interests or online. However, there were many more examples of young people struggling with friendships and peer relationships, with peers not understanding, or worse disbelieving, their need for support or bullying them. These problems were described by caregivers and young people regardless of whether they had reported a young person had a mental health condition. Some young people chose not to tell friends about their condition for fear of their reaction or because they felt ashamed of their condition.

Difficulties with integrating with peers took their toll on young people’s self-esteem and wellbeing. They reported feeling different from their peers because of living with their condition, their exclusion from activities, and from having experiences that were not shared with their peers. These differences could leave them feeling left out and lonely, or depressed:

“I had to mature quicker than most my age because of my circumstances and have difficulty relating to those of my own age and connect better to people who are older than me. My friends from school will not know what this side of life looks like and sometimes it’s lonely. My friends from childhood with medical conditions have all passed away, so processing that so young was daunting and confusing.” Young person-H with a prosthetic eye and other conditions.

Some caregivers thought that their children had not matured as much as their peers in their adolescence because their health condition and frequent school absences meant that they had missed out on socializing and opportunities for independence, which left them lacking in self-confidence and self-worth, or easily led by others.

Theme 3. The vital importance of staff support for young people with chronic health conditions: “sometimes the staff do not know what is best and do not always involve you in the conversations”

We constructed three sub-themes related to staff support for young people with chronic health condition: “A need for reassuring and encouraging behavior from staff”; “A lack of staff support could hinder young people’s motivations to succeed”; and “Gaps in staff knowledge.”

A need for reassuring and encouraging behavior from staff

Many young people, caregivers and staff reported that reassurance, empathy, and care from individual staff could make a huge difference to their child’s wellbeing. Two caregivers and one staff member said that they thought young people would benefit from a school staff member reaching out to them at home while they were absent to make them feel connected and support their remote learning:

“Contact the pupil, not the parent so that they feel included. Just ring them up for a chat. Send a postcard home. Or why not even make a short home visit. Since the pandemic, the online model is a really useful one for children.” Caregiver-Q of YP with ME/CFS.

In positive examples that participants gave, there was a sense of the staff member “knowing” the young person, their personality, history, and needs, and “checking-in” with them to ask them how things were going with their schooling:

“My English teacher... really understood me and my anxieties. She always reassured me when needed. She always told me to believe in myself especially on the days when I did not... These were all small things she’d do for me but made me feel that I always had someone to support me when needed.” Young person-E with anxiety and another condition.

Some participants highlighted the need for staff to help young people with chronic health conditions integrate with their peers. Several staff and one parent highlighted positive examples of staff proactively making sure pupils did not miss out on opportunities to socialize, to feel a part of the class, or explain their condition (if a pupil desired it). Several caregivers and young people expressed desires for this type of support.

Many participants highlighted that listening to pupils’ views about the support that they needed was integral as it enabled young people to feel safe, express their needs, and have autonomy over their school life and their condition. When staff were indifferent, callous or

disbelieved their condition, particularly if their condition was not visible, it caused significant distress to the young person and caregivers, exacerbating the young person's isolation, feelings of low self-esteem, and sense that they were misunderstood:

"Teachers and staff can mistake absence through illness for not wanting to be in school. These children are often desperate to go to school and succeed." Caregiver_Q of YP with ME/CFS.

"Physical health was seen as 'real' by the headteacher, mental health was not. Absences should have been authorised and CAMHS [Child and Adolescent Mental Health Services] advice should have been followed." Caregiver_A of YP with anxiety and another condition.

A lack of staff support could hinder young people's motivations to succeed

Young people highlighted the importance of support from staff to succeed academically. A few caregivers reported that there was no extra tuition for their child to help them catch-up on the work that they had missed and several young people said they had been rebuffed by staff when they had asked for help. Two young people with physical conditions and one caregiver said that the responsibility to catch-up and attain was left with the young person. The young people highlighted that they had made extensive efforts to catch up and achieve academically:

"I managed to get the top grades in the whole year group... with determination and resilience. Despite my strong support system of teachers, family and friends, as someone with both visible and invisible medical conditions, others can really underestimate your potential. But I also love to prove people wrong, so I worked thrice as hard to get twice as far." Young person-H with a prosthetic eye and other conditions.

While one young person and one staff member reported positive support put in place by staff to succeed, many young people with physical conditions (and one young person who had also reported a mental health condition) described how their ability to achieve had been "underestimated" by staff, for example, by lowering their predicted grades, or they had been given "limited choices" for the subjects they could take:

"The school failed me massively, which has continued to negatively affect my mental health. My GCSEs were all withdrawn, and I had to concentrate on my core subjects only. I was held back a year because of low attendance by school management, which adversely affected my self-esteem and confidence." Young person-B with cystic fibrosis and other conditions.

Gaps in staff knowledge

Most participants reported that school staff having knowledge and/or training about a condition's physical and mental impact would enable and motivate staff to provide better support. Many staff gave comprehensive examples of how they had gained knowledge about a young person's condition through conversations with them, their

caregivers, medical professionals, and other staff members. Two staff reported receiving extra training in relation to a young person's health condition. In contrast, one senior and long-standing staff member reported that their school had only ever had one young person with a chronic health condition, suggesting some staff may be unaware of pupils with health issues.

Some young people and caregivers highlighted staff's lack of understanding and disbelief about the impacts of invisible illnesses such as cystic fibrosis and sickle cell anaemia, for example, because they did not physically appear unwell. However, one staff member also highlighted that putting the right support in place was also reliant on a young person being willing to share information about their condition. Several caregivers and many staff highlighted gaps in knowledge on how best to support young people with mental health problems and young people with special education needs:

"In my year 7 group this year I have a student with ASD [autistic spectrum disorder] and OCD [obsessive compulsive disorder]. I have found it really difficult to support this student as he needs constant reassuring... I do not feel like I've had sufficient training to deal with this particular student." Staff-E.

Young people and two caregivers reported that staff were unaware of their own lack of knowledge, thinking they understood when they did not, and two caregivers highlighted safeguarding concerns because staff did not understand the severity of their child's condition:

"The trouble with asthma is that so many children have it therefore teachers put all asthma sufferers in the same group. The teachers did not understand the severity of my daughter's asthma and that it can kill." Caregiver-AE of YP with asthma and other conditions.

Discussion

Principal findings

This study examined the breadth of school experiences among young people with highly varied chronic health conditions and found many commonalities. Participants described how frequent absences for episodes of ill health were difficult to manage emotionally and scholastically, affecting pupils' learning and leaving them feeling isolated from their peers, substantiating findings from previous studies (Dyson et al., 2010; Hopwood et al., 2024; Spencer et al., 2023a). However, absence was also unavoidable due to fatigue, pain or other symptoms related to a young person's condition(s), or because medical appointments were scheduled during school hours, which were outside young people or caregivers' control.

There is limited evidence that absence explains the association between chronic health conditions and lower attainment (Beynon and Thomson, 2022; Jay et al., 2023). Our findings suggest that while absence may contribute to lower attainment for young people with chronic health conditions due to missed learning, there may be multiple other causes, including: the direct impacts of the underlying condition on cognition and behavior; symptoms of the condition causing fatigue and affecting concentration;

difficulties managing anxiety caused by falling behind and isolation from peers; distress caused by staff indifference to pupils' health and wellbeing needs; and a lack of school support to catch up with missed work and help young people achieve their academic goals. Young people and caregivers reported that reassurance and care from even one staff member was valued and remembered, echoing other studies' findings (O'Hagan et al., 2022; Spencer et al., 2023b).

Implications for policy and practice

Due to the association between school absence and attainment and other detrimental social outcomes, the Children's Commissioner for England has campaigned for 100% attendance for all pupils (Children's Commissioner, 2023). Current statutory guidance on school absence in the England recognizes that pupils with chronic health conditions face more complex barriers to attendance and says that their right to an education is the same as any other pupil, "therefore the attendance ambition for these pupils should be same as it is for any other pupil" (Department for Education, 2024a, p. 23). However, our study shows that young people with chronic health conditions could not avoid absence and needed a more flexible and equitable "attendance ambition" suited to their needs. Participants wanted their efforts to engage in education while managing poor health to be recognized and celebrated, rather than narrowing academic engagement to physical presence in school (Estévez et al., 2021; Kearney and González, 2022). Widening the ways in which young people with chronic health conditions can participate in education, for example, through hybrid or virtual learning, experiential and community-based learning, could support their academic ambitions (Bonfield et al., 2020; Kearney and González, 2022; Lucas et al., 2020; Wilkie, 2014). Studies have also shown that continued contact between pupils and their teachers and classmates through prolonged sickness absences improved young people's sense of wellbeing and their transition back into school life (Capurso et al., 2025; Hen, 2022).

Schools are increasingly seen as a key partner in supporting children's health and wellbeing (Department for Education, 2024a, 2025). The diversity of health conditions within our sample of young people and caregivers underscores the imperative for school staff to follow existing guidance which states that schools should seek to understand the nature of individual pupil's needs and work in partnership with young people and their families and external agencies to put the right support in place (Department for Education, 2015, 2024b). However, evidence highlights that schools' capacities to engage in communication, information-gathering, and coordination work is limited when it is unrelated to teaching responsibilities (Herlitz et al., 2025; Van Clooster et al., 2018; Verger et al., 2020), particularly given the post-pandemic rise in pupils with complex needs (Centre for Social Justice, 2024). To effectively engage with health and other support services to improve young people's attendance and support them to access education, schools will likely need additional resource and specific staffing roles.

Implications for research

Research on school experiences and interventions for young people with chronic conditions typically focuses on individual health conditions (Spencer et al., 2023b), or on singular contexts, e.g., hospitalization or school avoidance (Capurso et al., 2025; Lester and Michelson, 2024; Tougas et al., 2023). Although small-scale, our study evidences the diversity of health conditions, including co-morbid health and mental health conditions. There may therefore be value in developing interventions which focus on common education-related needs among young people with chronic health conditions (Spencer et al., 2023a) and parental engagement (Lester and Michelson, 2024). Interventions might have specific content related to key areas of difference among conditions, for example, the degree to which children need help during illness and treatment, absence patterns, visibility of condition (Broholm-Jørgensen et al., 2022), important family contextual factors (for example, low income, additional health problems), and available health and wellbeing statutory and community support services (Lester and Michelson, 2024). Interventions could potentially be led by education, clinical or local authority settings. Although there may be small numbers of young people in individual secondary schools with chronic health conditions, across a local authority there would be a sizeable number of pupils that may benefit from additional support, akin to the way that local authority employed Virtual School Heads support the education and wellbeing of looked after children (Drew and Banerjee, 2019; Sebba and Berridge, 2019).

Further research is needed to evaluate the effectiveness of staff training on improving staff awareness of and responses to pupils with chronic conditions. Participants' reports suggest that staff training in supporting young people with special educational needs, anxiety and other mental health conditions to attend school would be valuable, particularly since there are growing numbers of pupils with these challenges (Cybulski et al., 2021; Deighton et al., 2019; Hunt et al., 2025). Existing evidence on mental health training interventions suggests that staff training can improve staff awareness, knowledge and confidence around pupils' mental health, however, there is weak evidence for whether training leads to actual changes in staff behavior or improved pupil's outcomes (Anderson et al., 2019; O'Connell et al., 2021; Pierret et al., 2022). It may be that drawing attention to pupils with chronic health conditions as part of school improvement plans, rather than a narrower focus on training, could foster a more inclusive and welcoming school environment for all pupils, especially if plans are informed by young people with chronic health conditions (Sandoval and Messiou, 2022; Wang et al., 2023).

Strengths and limitations

This study was able to triangulate the experiences of caregivers, young people and school staff to identify common experiences across young people with a wide range of different health conditions. In particular, there was a large and diverse sample of caregivers, enabling us to see a saturation of themes within their sample. The online survey enabled us to reach participants across England who may not have been able to participate in-person. However, we did not achieve data

saturation with the young people and school staff samples, for which we experienced challenges in recruitment. Although we contacted many organizations that worked with young people with health conditions, perhaps we needed more effective promotional materials and to have promoted the study further via social media. We did not ask young people for their exact age or current educational position which might have provided valuable contextual information. There was high missingness for gender in our survey of young people and caregivers.

Our findings may not be representative of all school staff or all young people, for example, it may not be representative of young people with English as a second language, with poorer literacy, or who feel more disengaged from education. We did not explore social patterning in experiences of school absence (due to our small sample size). Future research could explore whether young people and caregivers perceived that disadvantage (i.e., financial hardship), having special education needs or disabilities, or ethnicity affected pupils' experiences of school absence and return. Furthermore, our findings may not be representative of school experiences outside of England.

Conclusion

Young people with chronic health conditions cannot avoid absence from school and need staff support to help them catch-up with their studies and continue to feel a part of the school community, based on multiple informants' accounts. Policy and practice should focus on mitigating the impact of health-related non-attendance by giving young people care and reassurance, widening the ways in which young people can participate in education, and involving young people and caregivers in discussion about learning needs and school participation.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving humans were approved by University College London Research Ethics Committee. The studies were conducted in accordance with the local legislation and institutional requirements. Written informed consent for participation was not required from the participants or the participants' legal guardians/next of kin because participants were considered old enough at age 16+ to reflect on and share their school experiences. Participants were able to withdraw at any point during the survey. We acknowledged during the informed consent procedure that while the survey questions themselves should not be unduly stressful, remembering poor experiences of support might be. We highlighted that participants could skip any questions they did not wish to answer. We provided a debrief sheet with contacts of organizations for support.

Author contributions

LH: Conceptualization, Formal analysis, Investigation, Methodology, Writing – original draft, Writing – review & editing. MJ: Writing – review & editing. CP: Conceptualization, Writing – review & editing. JD: Writing – review & editing. RG: Writing – review & editing. RB: Writing – review & editing.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Generative AI statement

The authors declare that no Gen AI was used in the creation of this manuscript.

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Supplementary material

The Supplementary material for this article can be found online at: <https://www.frontiersin.org/articles/10.3389/feduc.2025.1600751/full#supplementary-material>

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