

Teaching for Life

Full Report

Teaching for Life is a collaborative project between the Faculty of Education and the Faculty of Health and Wellbeing at Canterbury Christ Church University.

Ian Durrant
Sally Robinson
Alison Ekins
Kathryn Summers
Hannah Jones

Contact Dr Sally Robinson
E mail sally.robinson@canterbury.ac.uk
Telephone 01227 782309
Address School of Public Health, Midwifery & Social Work,
Faculty of Health & Wellbeing,
Canterbury Christ Church University,
Canterbury,
Kent
CT1 1QU

Copyright

© Canterbury Christ Church University 2014

All rights reserved. No part of this publication may be reproduced, modified, amended or stored in any retrieval system, or transmitted, in any form or by any means, without prior permission of Canterbury Christ Church University.

ISBN 978-1-909067-48-6

www.canterbury.ac.uk

Contents

	<i>page</i>
Executive summary	iii-iv
1. Introduction	1
2. Previous Research	2
3. The Research Project	3
3.1 Questionnaire	3
3.2 Interviews	4
3.3 Results	6
3.4 Conclusions	28
4. Recommendations	31
References	33
Appendices	
Appendix 1 Questionnaire	34
Appendix 2 Interview questions	39
Appendix 3 Medical glossary	40
Appendix 4 Educational glossary	44

Executive Summary

There are increasing numbers of children with life limiting or life threatening conditions in mainstream schools. Previous research shows that the needs of these children are not being well met. The symptoms of their condition and its treatment can interfere with a child's whole school experience including their learning, their self-esteem and their relationships. Many children and parents feel under supported by schools. One study showed that teachers report an insufficiency of information resources or guidance for themselves in relation to having children with cancer in their school. In England, the Children and Families Act (2014) aims to bring about better integration of health care, social care and education for these children.

The Teaching for Life project aimed to explore the needs of teachers in relation to working with children with life limiting or life threatening conditions. It comprised an on-line questionnaire, completed by 90 teachers mostly from mainstream schools in south east England, and interviews with 38 teachers who were undertaking the Special Educational Needs Coordination training for special educational needs coordinators (SENCOs). Six members of staff from a Special school were also interviewed.

The study showed that the most common life limiting or life threatening condition to be reported by the teachers was cancer followed by cerebral palsy, Duchennes muscular dystrophy and cystic fibrosis. There was a wide variance across schools about who was responsible for keeping medical and care needs of pupils updated. About half the teachers in this study had provided medical care for a child. Many teachers were anxious and concerned that meeting a child's medical needs in school was very challenging and some felt that they were failing children. Teachers want better and quicker access to information and support related to providing medical care and administering medicines in particular.

Teachers recognised the need for good multi-disciplinary working around the child, but there were a number of barriers. These included teachers not always understanding which health care professionals could support them, or how to contact them, delays in the school receiving medical information from health care professionals, health care professionals not being able to provide the right kind of information at the right time, and the difficulties with getting the right professionals together for a meeting.

Parents were cited as a key source of information and guidance for teachers who want to understand the medical and non-medical needs of a child. However parents' own emotional trauma made this vitally important communication extremely difficult. Teachers felt a strong professional responsibility to be informed and to try to find support for themselves and the child, but their inability to get sufficient information or support from the parents, health professionals or the school, meant that many turned to what they could find on the internet.

Teachers described themselves as floundering at the centre of an emotional web, as they tried to balance the needs of the child with the condition, their parents, other pupils and their parents, themselves and other staff, all within a school culture that could feel insecure and uncertain. Some spoke of the subject being 'taboo', and everyone not knowing whether they could or couldn't 'talk about it'. Teachers recognised that they needed support with the emotional strains that are associated with having a child with a life limiting or life threatening condition in school. Teachers wanted certainty and clarity. They wanted to work within a clear framework that provides clarity about school

processes and decision making, in respect of issues such as the recording of pupil absences and pastoral support when a child has a life limiting or life threatening condition.

Teachers wanted to be better equipped for communicating with the others about serious illness, death and bereavement. They wanted relevant educational resources that could provide a structure for their teaching and from which they could model what to say, what to do to and how to be a really supportive teacher in this difficult situation. They wanted to understand more about how life limiting and life threatening conditions affect children emotionally and behaviourally, and strategies for dealing with the outcomes. The experience of teachers who had worked with children with life limiting or life threatening conditions could be usefully shared with teachers for whom this is a new experience.

In summary, teachers were well aware of the medical, emotional and social needs of both the child and the other children and adults that surround that child, as well as the importance of the physical attributes of the building and the culture of the school. They wanted more information, guidance and support. Teachers need emotional support for themselves if they are to be able to contain their own anxieties and be able to support others, and in turn they need to be supported by a whole school approach to emotional health and wellbeing, which includes addressing bullying and inclusion. Collaboration between themselves and inter-professional health and social care agencies needs to work more effectively.

1. Introduction

There are increasing numbers of children living with serious health conditions who might have died in the past, but for advances in medicine. For example children with cancer and cystic fibrosis are much more likely to live into adulthood than previously (Gatta et al, 2005; Simmonds, 2013), and be engaged in education.

Life limiting conditions are those from which there is no reasonable hope of cure and from which children or young will die, and life threatening conditions are those for which curative treatment may be possible, but can fail. These include:

- Conditions where medical treatment might fail (e.g. cancer, organ failure and HIV/AIDS);
- Conditions where the child has long periods of intensive treatment and where premature death is possible (e.g. cystic fibrosis, Duchenne muscular dystrophy);
- Progressive conditions for which there is not cure (e.g. Batten's disease, muscular dystrophy, cerebral palsy, mucopolysaccharidoses);
- Conditions where children have a severe neurological disability which could lead to death (e.g. complex needs such as those following brain or spine injuries, severe cerebral palsy).

(based on Association for Children's Palliative Care, 2009)

Figure 1 Definition of life limiting and life threatening conditions used in the research

More than ever before, sick children are likely to undergo their treatment and recovery at home rather than in hospital. This means that they need on-going educational support from their school during times of absence, while at home, and support to successfully re-integrate back into their school when they are feeling well (St Leger and Campbell, 2008). Local Authorities in England are legally responsible for ensuring that suitable arrangements are made for the education of children who are unable to attend mainstream or special schools for 15 cumulative or consecutive days due to their illness (DfE, 2013). The Children and Families Act (2014) places a legal duty on schools to support children with medical conditions and defines any child who requires special education provision as having special educational needs (SEN). Some children will require multiple service support. The integration of health services, social services and education to support these children is at the heart of Government policy (DfE/DH, 2014). At the local level, integration is facilitated through the Health and Wellbeing Boards. For an individual child in a maintained school, it is facilitated through an Education, Health and Care (EHC) Assessment undertaken by the local authority which might result in an EHC Plan of how the services will work together around the child (NCICS, 2013).

2. Previous research

2.1 International literature review

An international review of academic papers published between 2005 and July 2010 (Robinson and Summers, 2012) found:

- Children with life limiting or life threatening conditions often find it very difficult to meet the expectations of schools due to their symptoms such as tiredness, nausea or pain; on-going treatment and its after effects; missing out on key points of learning; and living with a level of uncertainty about their future. Some children are also coping with changes in their appearance and stigma. Together these can diminish their self-confidence, interfere with their relationships and leave them feeling very isolated.
- Views from parents and children indicate that teachers need to have a better understanding of children's medical conditions as well as their social, educational and emotional needs. Teachers have an important role to play in facilitating peer contact, providing information to others, helping with reintegration back into school after an absence and providing support for siblings.
- In order to meet the needs of the children and their families, schools need to recognise that both the medical model, which focuses on the condition, and the social model, which focuses on the environment, have value. Ecological models, which recognise the real-life interplay of the home, school and health services were recommended by some authors.
- No published literature was found about teachers' views or experiences of working with children with life limiting or life threatening conditions.

2.2 Impact of cancer on children's primary school education

A UK children's cancer charity carried out research with a sample of primary aged children diagnosed with cancer; their parents, nurses and social workers; and teachers who worked in hospital schools (CLIC Sargent, 2012). They found:

- About a third of parents thought that their child's primary school kept in regular contact with the hospital school while their child was taught in hospital.
- About two thirds of parents felt well-informed about their child's education at primary school, after their cancer diagnosis.
- One third of the parents in their study had not been consulted about how their child's diagnosis was to be communicated to teachers and children at their child's primary school.
- Half (56%) of parents felt that their child had received sufficient support to enable their child to resume their education back at primary school after a stay in hospital.
- More than a third of parents reported that their child had been bullied or teased from peers due to their diagnosis or treatment.
- Nearly half of parents reported that their child had grown apart from friends.
- Almost half of parents said that their child's primary school had not facilitated contact between their child and their school friends during their child's absence from school.

2.3 Resources and guidance for teachers

The National Foundation for Educational Research (Pyle, 2013) reported that only 13% of 1580 teachers across maintained primary and secondary schools thought that there was enough information, resources and guidance available to teachers to support a pupil with cancer in school.

2.4 Conclusions from previous research

Research clearly indicates that the needs of children with life limiting and life threatening conditions, and their families, could be better met. Teachers in mainstream schools are central to bringing about improvements, but think they have insufficient information resources or guidance. There appears to be a paucity of research with teachers in *mainstream* schools about this subject.

3. The Research Project

Teaching for Life aimed to explore the needs of teachers in relation to working with children with life limiting or life threatening conditions. The research received approval through the university's ethical procedures and was carried out during May and June 2013. The research methods comprised a questionnaire and interviews.

3.1 Questionnaire

The on-line questionnaire included the definition of life limiting or life threatening conditions as expressed in Figure 1, and was structured into four different sections:

- Role in school
- Experience of working with children with a life limiting or life threatening condition
- Training and information sources
- Information about the school (type of school, location of school etc.)

(see Appendix 1)

The questionnaire was piloted; firstly it was sent to all members of the project team and then to a group of special educational needs coordinators (SENCOs). Following feedback, a few questions were changed to ensure clarity. Accompanying the questionnaire was a Participant Information Sheet which outlined the aim of the study, assured confidentiality and anonymity, and provided the researchers' contact details.

The questionnaire was sent by e mail to 550 teachers who had completed, or who were undertaking, the National Award for Special Educational Needs Coordination training for SENCOs in the south east of England. Each recipient was asked if they would complete the questionnaire and, in addition, to forward it to staff such as head teachers, senior leadership team, teachers, teaching assistants and pastoral staff in *mainstream* schools who had experience of working with children with life limiting or life threatening conditions.

Ninety completed questionnaires were returned; a response rate of 16.4%. 60% (54) were from the south east of England, seven were from London, two were from the east of England and a further two from the south west. Forty one (45.6%) of the respondents were working in a state funded (Primary, Junior or Secondary) school, 16 (17.8%) were working in an Academy. Seven were working in either in a Comprehensive, High, Grammar, Independent or Special school, and one was working in a Pupil Referral Unit. Twenty five respondents neither identified their location nor the type of school in which they were working.

	Respondents' roles (n=90)	WITH (n=53)	WITHOUT (n=37)
SENCO	55	33	22
Class/Form teacher	22	13	9
Inclusion manager	15	6	9
Senior leadership team(head teacher, assistant head teacher, deputy head teacher)	18	13	5
School governor	2	1	1
Teaching assistant	1	1	0
Teacher with regional responsibility for students with physical and medical needs	1	1	0
Key Stage 1 lead	1	1	0

Table 1 Questionnaire respondents WITH or WITHOUT experience of working with children with a life limiting or life threatening condition and job role

Respondents were given a list from which to identify their role, and were able to choose multiple options as it is acknowledged that some roles overlap. Table 1 shows that over half (55) the respondents identified themselves as SENCOs (61.1%), 22 as class/form teachers (24.4%) and 15 (16.7%) as inclusion managers. Two were head teachers and 16 were either assistant or deputy head teachers. The remainder did not answer this question.

Fifty three respondents (59%) identified that they had direct personal experience of working with a pupil with a life limiting or life threatening condition and, for the purposes of the study are defined as respondents 'WITH' experience (please note 3.3.1). Thirty seven (41%) had not and are defined as respondents 'WITHOUT' experience. Of the 37 WITH experience, 21 described themselves as working in a rural location, 16 in an urban location and two in an inner city.

3.2 Interviews

Group and individual interviews were carried out in the south east of England with SENCOs who were undertaking the S.E.N. Coordination training for special educational needs coordinators (SENCOs). SENCOs were informed about the research and provided with a Participant Information Sheet in advance of volunteering to participate.

Experience	Number of participants per interview	Type of school (participants)	Participants
WITH	3	Primary (2) Secondary academy (1)	SENCOs who were undertaking training
	3	Primary (3)	
	4	Primary (3) Secondary (1)	
	1	Infant (1)	
	6	Primary (2) Primary academy (1) Secondary grant maintained (1) Secondary (1)	
	3	Primary (1) Secondary (1) Special (1)	
	6	Special school (4 teachers, 1 link practitioner, 1 therapy assistant)	
WITHOUT	2	Primary (2)	SENCOs who were undertaking training
	4	Infant/nursery (1) Primary/nursery(2) Secondary academy (1)	
	4	Primary (3) Secondary (1)	
	1	Primary (1)	
	3	Primary(3)	
	4	Primary (2) Junior (1) Secondary (1)	

Table 2 Interview participants WITH or WITHOUT experience of working with children with a life limiting or life threatening condition and type of school

Table 2 shows how participants were split into groups comprising those 'WITH' experience of working with children with life limiting or life threatening conditions in *mainstream* schools and groups of those 'WITHOUT' that experience. In addition, one group ('WITH') was carried out with a cross section of staff in a Special School where staff were known to have extensive experience of working with children with life limiting or life threatening conditions.

Each group was led by a facilitator, attended by a note taker. After introductions, the facilitator rephrased the aim of the research and checked that the participants were happy to proceed and to be audio recorded. The facilitator asked slightly different open questions to the WITH groups compared to the WITHOUT groups (see Appendix 2). At the end of the interview each participant was provided with information about the charities Cruse Bereavement Care and Together for Short Lives, and the researchers stayed to provide support if needed, and to answer any questions.

The analysis was interpretive. The facilitator and note taker agreed key emerging themes immediately after each interview had been concluded. These were interrogated and modified through listening back to the audio recording, and sub-themes were identified. The analysis of all the WITH interviews were combined to produce an overall picture of the 'WITH experience'. The same process was repeated for the 'WITHOUT experience' interviews. The themes and sub themes were presented as spider diagrams to the research team who agreed that they were a fair representation of the discussions.

Two researchers worked on the report and agreed the final analysis and narrative. The final report was agreed by a school nurse consultant to the project and the research team.

3.3 Results

3.3.1 The range of life limiting and life threatening conditions in schools

How many pupils are there in your school with life threatening or life limiting conditions and what is the nature of their condition?

Condition as recorded by the respondents <i>*is not a life limiting or life threatening condition according to the ACT (2009) definition</i>	Number of respondents who knew 1 pupil	Number of respondents who knew 2 -4 pupils	Number of respondents who knew 5 or more pupils
Severe allergies*	22	2 (4-8 pupils)	2 (10 or more pupils)
Asthma*		2 (4-8 pupils)	2 (10 or more pupils)
Cancer (leukaemia, brain tumour)	11	1 (2-4 pupils)	
Cerebral palsy	4	2 (4-8 pupils)	
Diabetes*	4	2 (4-8 pupils)	
Duchennes muscular dystrophy	4	1 (2-4 pupils)	
Cystic fibrosis	5		
Heart condition	5		
Profound and Multiple Learning Difficulties*			1 (5 or more pupils)
Epilepsy	3		
Tracheotomy		1 (2-4 pupils)	
Downs syndrome	2		
Haemophilia*	2		
Kidney transplant	2		
Alexander's disease	1		
HIV	1		
Spinabifida/hydrocephalus	1		
Hip dysplasia*,Respiratory difficulties & severe curvature of spine affecting internal organs*, Neuropathy*, Neurofibromatosis*, Trachobonchomalasia*, Diamond blackfan anaemia*, Monotonic dystrophy*, Limb girdle MS*, Heart murmur* and Robinow'ssyndrome*, Congenital diaphragmic hernia*, Motor and sensory*, Russell- Silver syndrome*, Respiratory difficulties*,Carotid artery problems*	1		

Table 3 The nature of pupils' conditions in schools at the time of answering the questionnaire

Table 3 shows that some respondents cited conditions which are not life limiting or life threatening according to the definitions included in the questionnaire (Figure 1). Some

appeared to have interpreted 'life limiting' in the general sense of a condition which can 'threaten life', such as severe allergies and asthma. Therefore the 53 (59%) respondents who identified themselves as having had direct personal experience of working with a pupil with a life limiting, and are defined as 'WITH' experience in these results, needs to be understood within this context. The true figure is likely to be less than 59%. Some children have both a condition that can 'threaten life' as well as a 'life limiting' condition.

Have there been any pupils with life limiting illnesses or life threatening conditions in your school in the last 5 years (excluding any identified in the previous question)? If so, how many people have there been and what was the nature of their condition?

Condition as recorded by the respondents <i>*is not a life limiting or life threatening condition according to the ACT (2009) definition</i>	Number of respondents who had known 1 pupil	Number of respondents who had known 2 -4 pupils	Number of respondents who had known 5 or more pupils
Cancer (leukaemia, brain tumour)	12 (12 pupils)	5 (2-4pupils)	
Unknown condition	4 (4 pupils)	1 (2-4 pupils)	1 (more than 5 pupils)
Heart condition (diagnosed & undiagnosed)	5 (5 pupils)		
Cerebral palsy	1 (1 pupil)	1 (2-4 pupils)	
Duchennes muscular dystrophy	3 (3 pupils)		
Cystic fibrosis	2 (2 pupils)		
Epilepsy	2 (2 pupils)		
Allergies*, Diabetes*, Lupus*, Myasthenia Gravis*, Osteogenesisimperfect*	1 (1 pupil)		

Table 4 The nature of pupils' conditions in respondents' schools during the last five years

When asked to consider their school over the last five years, and exclude the current situation, 12 respondents to the questionnaire answered that there had been one pupil, and five answered that there had been between two and four pupils, with either leukaemia or brain tumours in their school. This was followed by pupils with heart conditions.

The findings from Table 3 and 4 together suggest that respondents had the highest number of pupils with cancer in their schools followed in decreasing order by cerebral palsy, Duchennes muscular dystrophy and cystic fibrosis.

3.3.2 Current information and support for teachers

How are you made aware of the existence of a pupil with a life limiting or life threatening condition and their needs in your school?

Responses as recorded by respondents	Respondents (% of 90 respondents)	WITH (% of 53 respondents)	WITHOUT (% of 37 respondents)
Parents	42.2% (38)	56.6% (30)	21.6% (8)
Pre-admission /transition meeting (from previous schools and classes)	22.2% (20)	20.8% (11)	24.3% (9)
SENCO	10% (9)	13.2% (7)	5.4% (2)
Staff meeting	8.9% (8)	9.4% (5)	8.1% (3)
Health plans/medical reports	5.6% (5)	5.7% (3)	5/4% (2)
Medical staff	5.6% (5)	7.5% (4)	2.7% (1)
Head teacher	4.4% (4)	5.7% (3)	2.7% (1)
Outside agencies e.g. social worker	4.4% (4)	5.7% (3)	3.7% (1)
Details displayed in staff room	3.3% (3)	3.8% (2)	2.7% (1)
School nurse	3.3% (3)	3.8% (2)	2.7% (1)
Annual medical list	3.3% (3)	3.8% (2)	2.7% (1)
Statements of special educational need	2.2% (2)	3.8% (2)	
School information management systems & Education improvement plans	2.2% (2)	1.9% (1)	2.7% (1)
Specialist nurse (Ellenor)	2.2% (2)	3.8% (2)	
Doctors' letters	1.1% (1)	1.9% (1)	
Report from professionals (e.g. educational psychologists)	1.1% (1)	1.9% (1)	
Senior leadership team meetings	1.1% (1)		2.7% (1)
Training	1.1% (1)		2.7% (1)
Family and Inclusion leader	1.1% (1)		2.7% (1)

Table 5 Awareness of a pupil with a life limiting or life threatening condition

Who is responsible for updating information related to a pupil's medical and care needs?

Responses as recorded by respondents	Respondents (% of 90 respondents)	WITH (% of 53 respondents)	WITHOUT (% of 37 respondents)
SENCO	40% (36)	43.3% (23)	35.1% (13)
Office staff	22.2% (20)	22.6% (12)	21.6% (8)
Inclusion manager/leader	10% (9)	13.2% (7)	5.4% (2)
Head teacher	7.7% (7)	5.5% (3)	10.8% (4)
Class teacher	5.6% (5)	9.4% (5)	
Teaching assistant	3/3% (3)	5.5% (3)	
Family liaison officer	3.3% (3)	1.9% (1)	5.5% (2)
Parents	3.3% (3)	5.5% (3)	
First aider	2.2% (2)	3.8% (2)	
School nurse	2.2% (2)	1.9 (1)	2.7% (1)
Student services manager, SEN Governor, Health professional, Central Information System, Depends who parents share the information with, No one has been allocated this role, The leader of the unit where the pupil belongs – usually the Physically Disabled unit	1.1% (1)	1.9% (1)	
Medical teaching assistant, School health co-ordinator, Class teacher, Medical officer or Additional needs manager, A mini-computer support officer – pastoral, Home school worker, Designated member of staff	1.1% (1)		2.7% (1)
“School clerical workers put information on School information management system. Trained first aid higher level teaching assistant works with School Nurse and parents to produce and review care plans and to check medicine is in date.”	1.1% (1)		2.7% (1)

Table 6 Person responsible for updating information about a pupil's medical and care needs

Most respondents became aware of a child with a life limiting or life threatening condition from the parents (42.2%) or via a meeting (22.2%). When asked about the frequency of updating information about the child's medical needs, responses varied from monthly to annually but most commonly, annually (33.3%) or 'as regularly as it needs to be changed' (31%). As shown in Table 6, there was a very wide range of responses when identifying who updated information relating to a child's medical and care needs. The most common answer was the SENCO (40%), followed by the office staff (22.2%).

What other sources of information would you consider using to supplement your understanding of the MEDICAL care needs of pupils with life limiting or life threatening conditions?

Sources of information	Respondents (% of 90 respondents)	WITH (% of 53 respondents)	WITHOUT (% of 37 respondents)
Parents/carer	83.3% (75)	83% (44)	83.8% (31)
Paediatrician	75.6% (68)	77.4% (41)	73% (27%)
School nurse	70% (63)	67.9% (36)	73% (27)
Occupational therapist	65.5% (59)	73.6% (39)	54% (20)
The pupil themselves	62.2% (56)	62.2% (33)	62.1% (23)
Websites	60% (54)	62.2% (33)	56.8% (21)
Physiotherapist	57.8% (52)	64.2% (34)	48.6% (18)
General practitioner	55.6% (50)	58.5% (31)	51.4% (19)
Text books	24.4% (22)	28.3% (15)	18.9% (7)
SENCO	37.8% (34)	41.5% (22)	32.4% (12)
Siblings	11.1% (10)	11.3% (6)	11.8% (4)
Other	8.9% (8)	11.3% (6)	5.4% (2)

Table 7 Teachers' sources of information about the medical care needs of children with life limiting or life threatening conditions

What additional sources of information would you consider using to supplement your understanding of the NON-MEDICAL needs of pupils with life limiting or life threatening conditions?

Sources of information			
WITH <i>(% of 53 respondents)</i>		WITHOUT <i>(% of 37 respondents)</i>	
Parents/Carer	42 (79.2%)	Parents/Carer	26 (70.2%)
The pupil themselves	37 (69.8%)	The pupil themselves	22 (59.5%)
Websites	32 (60.4%)	School Nurse	20 (54.1%)
Paediatrician	29 (54.7%)	Websites	18 (48.6%)
School Nurse	25 (47.2%)	Paediatrician	15 (40.5%)
Occupational Therapist	26 (49.1%)	SENCO	14 (37.8%)
General Practitioner	22 (41.5%)	Occupational Therapist	12 (32.4%)
Physiotherapist	21 (39.6%)	Physiotherapist	11 (29.7%)
Text Books	20 (37.7%)	Text books	10 (27.0%)
SENCO	18 (34.0%)	General Practitioner	7 (18.9%)
Siblings	10 (18.9%)	Parents/Carer	26 (70.2%)
Common Assessment Framework Assessment	1 (1.9%)	Siblings	5 (13.5%)
Educational psychologist	1 (1.9%)	Early intervention team	1 (2.7%)
Friends/family/colleagues with specialist experience/training	1 (1.9%)		
School counsellor	1 (1.9%)		
Specialist Teachers	1 (1.9%)		
Staff at other schools	1 (1.9%)		
STS	1 (1.9%)		

Table 8 Teachers' sources of information about the non-medical needs of children with life limiting or life threatening conditions

Parents

Table 5 shows that most respondents to the questionnaire (42.2%), and more especially those WITH direct experience of working with a pupil with a condition (56.6%), learnt about the existence of such a pupil and their needs from parents. Thereafter parents continued to be the most commonly mentioned source of information about the child's medical care (83.3%) and non medical care needs (70.2%; 79.2%)(Table 7& 8). Parents were also identified as an important source of on-going information and support during the interviews. Participants WITHOUT experience believed that they would be reliant on parents and that a good relationship with parents would not only be essential, but very worrying if they didn't have it. They thought that parents would be a key source of information.

'Speak to the parents, because the parents will obviously have information'(WITHOUT)

Parents were people whose needs and choices needed to be respected,

'You'd need to have a close relationship with the parents as well to know that you're not saying something they don't want you to say and that they haven't broached with the child. Yeah eggshells all the time, isn't it?' (WITHOUT)

Teachers looked to parents as their guide to sensitively working out what role they needed to play.

'I think it's going to be very dependent on the parents, because if you've got proactive parents who are confident communicators with professionals it's probably going to be more cohesive, but if you have parents who are less confident, younger, who are not able to ... manage significant issues in their lives themselves, it's going to fall more to the school to be the ones going out looking to see what's out there because if it isn't coming from the medical people then the school is going to have that responsibility because they're the people seeing the child on a day to day basis.' (WITHOUT)

These perceptions were supported by the comments made by participants WITH experience, but they spoke more about parents alongside the needs of the whole family. They also discussed the emotional challenges for teachers more fully. They explained that parents are not always emotionally ready to talk about these issues. They said,

'Liaison with the parents, that's the thing that is just so critical, to talk to the parents all the time. It's the most hideous time for them, but pretending it's not happening or ignoring it is just the worst thing' (WITH)

'He and his parents didn't want to really even discuss it, because I think the parents were so devastated and angry' (WITH)

'Some days they could talk about it – some days they couldn't. The child had a brother so the mother had to stay strong' (WITH)

Pupils

Approximately two thirds of the respondents turned to the pupils themselves for information about the medical and non-medical needs of that pupil (Table 7 & 8). Throughout the interviews, trying to best meet the needs of pupils with the life limiting or life threatening conditions was a thread that ran through everything that the participants said. They frequently reported their observations and their perceptions of the children's experiences, such as,

'He ... didn't want to really even discuss it' (WITH)

and *'... he went off and has chemotherapy'* (WITH),

'... they just fall through the gap. They didn't meet the criteria for this, they didn't meet the criteria for that and they need something more' (WITHOUT),

but gave no examples of direct discussions with pupils.

Health care professionals

After parents, respondents to the questionnaire looked to health professionals to supplement their understanding of the medical care needs of pupils. Table 7 shows that they cited paediatricians (75.6%), school nurses (70%), occupational therapists (65.5%), physiotherapists (57.8%) and General Practitioners (55.6%). Occupational therapists (73.6%; 54%) and physiotherapists (64.2%; 48.6%) were cited more by respondents WITH experience than those WITHOUT.

Table 8 shows that respondents WITH experience of working with children with a life limiting or life threatening condition cited a wider range of sources of information about children's non-medical needs than those WITHOUT experience. Those WITH cited General Practitioners (41.5%; 18.9%), occupational therapists (49.1%; 32.4%) and paediatricians (54.7%; 40.5%) more than those WITHOUT.

Regardless of being WITH or WITHOUT experience of working with children with life limiting or life threatening conditions, the participants in the interviews were concerned about the delays in communication and information from health care professionals. A typical comment was,

'I don't feel that I have a good, free and easy access to occupational therapists or speech therapists. I'm very frustrated ... how slowly the wheels turn.' (WITHOUT)

Participants discussed experiencing feelings of failing the children because their school had been unable to provide the proper care and support that a child needed. One said,

'We've got a couple of children where they're not life threatening, but they are significant conditions and they just fall through the gap. They didn't meet the criteria for this, they didn't meet the criteria for that and they need something more than we can offer them as a school, we need that other support and it isn't until you get to crisis point that anything seems to happen. And it doesn't seem fair for these children, that you are getting to crisis point and it's not fair for the school to not be able to support these children in the best way. Feeling like school is failing them, when in fact it's the external services.' (WITHOUT)

One of the SENCOs WITH experience said that she did not receive an important doctor's report until a long time after a situation had been dealt with. Discussing doctors' reports, another participant said,

'They're always supplied when a child moves into a new school. Sometimes it just takes a while to get them through, so if you were having a child who might have an emergency situation in school, you'd want to make sure you had everything in place on day one. Not for some children, oh it's alright we'll get it in 3 or 4 weeks' (WITHOUT)

An example of the risks that these delays incurred included,

'It's a concern with children with significant difficulties that it took some time for the epilepsy nurse to contact us to say that she needed to come in to do training and the child had actually been in school for about 6 weeks with this medicine that no one had been trained in administering' (WITHOUT)

School Nurse

Seventy per cent of respondents cited school nurses as a source of information about a child's medical care needs, and about half for information about non-medical needs. In the interviews, the participants WITHOUT experience often mentioned the school nurse as the person to whom they would turn on first finding out that they would be working with a pupil with a condition. They said,

'The school nurse, I guess, would be making links and be an important link'
(WITHOUT)

and

'I would hope the nurse would come in and say this is what we expect to happen, this is what your school needs to provide, if you can't do that then we need to find somewhere else for this child.' (WITHOUT)

However many participants WITH and WITHOUT experience of working with children with life limiting or life threatening conditions related mixed views about their working with school nurses. Some had found them to be extremely helpful, such as one who said,

'I've just had a child in my class diagnosed with a condition, it's not life threatening, but the school nurse took a big role and he has to have medication at school and it was all done by them, they arranged to come in and see me and explain what had happened and what the diagnosis was and how that was going to affect him and what my role in that would be. It was an automatic thing.'
(WITHOUT)

More typically others, such as this participant, described working with school nurses as,

'... quite 'hit and miss'.

She continued,

'... whether you can get hold of someone, whether they can actually... their ability to get hold of that information as well. And it's that sharing of information, if they're coming with that package of information that's really useful.' (WITHOUT)

Other participants also identified that sometimes school nurses were unable to deliver the specific information that the teacher most needed. For example,

'So the school nurse knows the children very well for a long time, but hasn't got the expertise, so when we're having the discussions about, "Is the skin as it should be?" or other issues going on she always says, "It's beyond my expertise...." So I think school nurse will sometimes ...have lots of general knowledge about things, but not necessarily specific knowledge. I think if it's a rare condition or something where there are going to be lots and lots of complications, you would need someone who really is able to give you as much advice as possible, because then you feel confident about where you're going and what you need to do' (WITHOUT)

Some participants WITH experience of working with children with a life limiting or life threatening condition reported having had almost no contact with a school nurse. Some of the participants WITH experience commented that it came down to the personal character of the nurse and goodwill. There were no clear procedures or structures to follow.

Internet

Sixty per cent of respondents turned to web sites in order to supplement their understanding about the medical needs of a pupil (Table 7).

Participants WITHOUT experience believed they would use sources such as the internet to find out information about the condition and to find out what resources were available for support.

'To be honest I would probably just try and research on the internet, or contact [place] Health to see if anybody could link me in the right direction from there' (WITHOUT)

'I would probable Google too, I often do that when I'm reading doctors' reports or things about children and there's a phrase that I don't understand or something I haven't come across before, then I would probably use Google' (WITHOUT)

Participants WITH experience not only cited turning to the internet slightly more than those WITHOUT experience for information about medical needs, but they cited it more (60.4%; 48.6%) for finding out about non-medical needs also. They described it as their responsibility, their professional duty, to carry out a good deal of research, but they had also done this because they thought that there were no other resources available to them.

'You're ending up taking on ownership for this child, the whole life, even though it's not your remit. You end up doing it because you don't know who the right people are to go and contact. I mean I had to do some research myself to find out who was available locally to get them to come into the school, because I didn't know. And there wasn't any of that on the plan; all I had was the parent who had special needs themselves' (WITH)

3.3.3 Teachers dealing with medical, educational and emotional needs

Medical needs

Have you ever been involved in providing medical care to a pupil with a life limiting or life threatening condition?

	Respondents (% of 90 respondents)	WITH (% of 53 respondents)	WITHOUT (% of 37 respondents)
No I haven't	48.9% (44)	41.5% (22)	59.4% (22)
Administering inhalers	23.5% (21)	24.5% (13)	21.6% (8)
Completing medical records	17.8% (16)	24.5% (13)	8.1% (3)
Administering oral medication	16.7% (15)	20.7% (11)	10.8% (4)
Physiotherapy	14.4% (13)	17% (9)	10.8% (4)
Feeding	8.9% (8)	13.2% (7)	2.7% (1)
Hygiene	7.8% (7)	13.2% (7)	
Administering injections	4.4% (4)	1.9% (1)	8.1% (3)
Changing dressings	4.4% (4)	5.7% (3)	2.7% (1)
Administering suppositories	2.2% (2)	1.9% (1)	
Administering other medication	1.1% (1)	1.9% (1)	
Overseeing (but not administering) injections	1.1% (1)	1.9% (1)	

Table 9 Teachers' sources of information about the medical care needs of children with life limiting or life threatening conditions

Table 9 shows that half the respondents (51.1%) had experience of providing medical care to a pupil with a life limiting or life threatening condition (please note 3.3.1). A quarter had administered inhalers (23.5%). Respondents WITH experience reported providing more medical care than those WITHOUT, and among those WITH a few reported experience of multiple procedures.

During the interviews, anxiety was expressed by participants WITH and WITHOUT experience, relating to dealing with the medical needs of these children in school. A typical comment was,

'I think people would be scared of getting something wrong or making a situation worse or not dealing with something in the correct way' (WITHOUT)

Many, particularly those WITHOUT experience, were concerned about schools being able to accommodate the children's needs in terms of changes to the timetable,

'Thinking about putting things in place, do they need extra support? Are they in a wheelchair? Are they only here in school for half days? Can they cope with whole days? What about trips? PE lesson? Playtimes? All the things that perhaps they would need some extra things in place, or not?' (WITHOUT)

and having appropriate physical space.

'Mobility, how that would affect the class room set up, toileting and things like that' (WITHOUT)

Those WITHOUT experience were concerned about the safe storage of medicines and the legal aspects of administering medication. For example,

'A room specifically designed for that (medication), a medical room even, we haven't got one of those, something like that would be needed I would have thought' (WITHOUT)

and,

'There's the legal aspect as well, if we're expected to provide medication and if it is wrong, are we then legally liable?... Ultimately you want to put the pupil first, but we still have to cover ourselves.' (WITHOUT)

Half (50%) of the respondents to the questionnaire had received formal training about the medical and care needs of pupils with a life limiting or life threatening condition. Of these, two thirds, were respondents WITH experience. In the interviews, concerns about administering medication were prevalent. Typically, one explained,

'They're frightened quite often to do erm certain things because they've got that fear of doing it wrong, not doing it correctly, at the wrong time' (WITH)

Both those WITH experience and those WITHOUT discussed the importance of training in relation to medication. For example, those WITHOUT experience said,

'Obviously, you'd have to have the correct training depending on how the medication was administered and have to make sure the parents were okay with a non-medical person administering it. But if parents consented and if the correct training had been undertaken it would probably be okay' (WITHOUT)

However for many, even when training was given, there were anxieties. One said,

'You've got to have the training and you've got to sign to say that you'd be willing to administer that and you do it with the absolute hope that you're never going to have to do it, but you do it because you feel you have to.' (WITHOUT)

Others spoke about needing the right type of training, at the right time, from the right person. For example,

'I've had more training and more understanding for example of the Epi-pen thing, than I've had of cancer, I mean I've learnt that from the 3 cases, from the parents as we've gone along, from reading stuff....' (WITH)

and,

'I requested the school nurse to come in and train staff on use of the Epi-pen, so we'd have the official training, but she couldn't train us until she had been trained and we still haven't had training. Some of the things we deal with sometimes are very complex and it's got to be that training from someone from a medical profession' (WITHOUT)

Even when training for staff was provided, administering medication or medical care needed to be understood within the context of the realities of school life. They said,

'If you're the class teachers, the one that's meant to be administering or the one that's had the training, then you've got to leave the rest of the class to go and do

that. Or if you're not, if that's someone else in school, the child's still got to get to that person' (WITHOUT),

'That situation could arise where the people that are trained either don't do it regularly, forget how to do it, are off sick, or not there for one reason or another. Then is that child allowed in school then? Should that child go home then because we can't provide the proper care for them' (WITHOUT)

and,

'... there'd be appropriate training so that if something did happen, you know, it might not just be your normal first aider on the playground. We'd need to know that we could cope with anything that might occur' (WITHOUT)

Educational needs and implications for teaching

Participants in the interviews spoke about the challenges of meeting the educational needs of children alongside the particular needs associated with children with life limiting or life threatening conditions. Initially some of those WITHOUT experience spoke about wanting to make lessons really fun because they assumed that the child would have a limited time to live. Comments included,

'I thought my goodness if I had a child like that in my class I'd want to make sure every lesson was really exciting, that was my initial thought. If a child had 6 months to live, it would be a massive influence on how you were teaching day to day I think. But I don't think a family would put a child in school if they only had 6 months to live, would they?' (WITHOUT)

and,

'So have you got to make it fun? And then how are you going to make it good without making things too different, so they're feeling more different than they do already' (WITHOUT)

Some recognised that the school may act as a stable and 'normal' environment for a child amongst all their hospital visits and treatment. It could be a place where they could feel 'normal' within their routine, as one said,

'The school's providing the stable environment, where they're just one of everybody else, whereas at home, in hospital, they're not getting that' (WITHOUT)

Many of those WITHOUT experience were most concerned about how they could make education relevant to a child with a life limiting or life threatening condition when schools are focused on academic achievement and results. One said,

'How do you make education relevant to someone with a life limiting illness? What's it for? What am I learning about? So much of what you feel you're driven towards in education is about the future, just as a general agenda. Of course it should be a bit more about the enjoyment of learning and all of that, but actually school is for qualifications, qualifications are for work, work is to earn money for your life and that might not be a stage that they ever reach' (WITHOUT)

This concern often led into further reflections about the purpose of education and its value. For example,

'I think there's a lesson for us all here, that it is that love for learning itself, rather than what the next step is. Throughout the whole of life, it's the value in the here and now, so perhaps it's looking at what we're doing in that respect as well'
(WITHOUT)

Those WITHOUT experience worried about their responsibilities to stick to the curriculum, which included the topic of death, and how they would deal with it.

'Some topics, PSHE for example in year 4/5 one of the topics is death and how you're going to approach that with a child in your class that's facing that is totally going to potentially totally change how you deal with it or whether you deal with it at all. But I'd imagine that also has consequences in other topics, history and things like that, I'd feel apprehensive about approaching the topic of death a lot more I think. So even when you're talking about Henry VII or beheading wives and things like that. You're still going to have connotations to not only that child but other children in the class and they'll know about this child that could die'
(WITHOUT)

Comments from participants WITH experience confirmed that having a child with a life limiting or life threatening condition impacted on the curriculum. Typically saying,

'They [parents] will say, yes we want them to have some work, no they're sick as a dog this week it's pointless' (WITH)

Some spoke of the curriculum becoming secondary to a child's medical needs, for example,

'Her learning was almost on hold for quite a large portion of time, which we were aware of but it became secondary really. It was the health need that had to become our primary concern' (WITH)

Nevertheless participants generally strived to avoid a child's education becoming seen as an 'add on' to the child's illness. In response to recognising that a child could not work at the same pace as other children, some had created bespoke timetables and flexible and individualised learning strategies so that the child could catch up.

'And then you have to do a bit of bespoke, catch-up teaching, you just do it, you have to find the time. So their profiles tend to be a little bit spikey' (WITH)

Those who had worked in special schools echoed this approach by saying,

'... all the children had some kind of severe learning difficulty, so they had some kind of severe need. So our teaching was quite individually based anyway, erm it was, as I say we only had 8-10 pupils in a class so you could focus very much on individual need' (WITH)

Some participants spoke of visiting a child at home to deliver work, and some supported parents who taught the child at home. As one said,

'We've done a lot more working with Mum, so she does quite a lot with him at home.... She was very keen to make sure that what he couldn't necessarily do in school, she could take on a home tutoring type role' (WITH)

Emotional needs of pupils, parents and staff

During the interviews, participants WITHOUT experience thought that a life limiting or life threatening condition could lead to behavioural problems. One said,

'Are there going to be any behavioural issues? Is the stress or the trauma of what's going on going to impact on the child's behaviour and then how are you going to manage that? (WITHOUT)

The participants WITH experience confirmed that pupils' attitudes, verbal and non verbal behaviour could become challenging. Some children had become used to one-on-one focused attention at hospital and being able to challenge doctors and nurses. On returning to school, they seemed unsure about how to speak to teachers appropriately. One participant explained,

'... he spent so long under medical care, talking to doctors and things where he'd be allowed to challenge them. He doesn't necessarily know how to speak to the adults in school appropriately and can come across as quite rude and quite blunt, the tone which he uses. And he also has a certain of 'well you can't punish me, because I could die before you'. He tries to take advantage of it and play it on an emotional level to the teachers' (WITH)

Another had been confronted with, "I'm going to be dead before you." They described feeling vulnerable and anxious about how to deal with these situations. One participant recounted,

'This girl had had behaviour changes, which everyone was going, oh she's got really naughty, she must have got into a bad crowd and we've only just found out, oh my goodness that's ... now I feel awful' (WITH)

An additional emotional strain on teachers was finding themselves caught in ethical dilemmas around the sharing of information about a child with a life limiting or life threatening condition. Those WITHOUT experience of working with such a child noted that dissemination had consequences for the feelings of parents of other children. One explained,

'Are your 'needing to know parents' via a letter, text or email, prior to ... assembly or whatever it's going to be, that your child age 4/5 is going to be privy to information about another child in school potentially dying. That's going to have consequences at home for them, that child's going to go home and ask questions' (WITHOUT)

and

'A lot of parents would like to have had that as a family time or a family way of dealing with it or discussing it. If you're taking that away from them that could open up another area of problems' (WITHOUT)

Participants WITH experience provided examples that confirmed these anxieties. Their examples often related to the broader problem of looking to parents as their guide, but finding parents who were struggling with their own emotional trauma. One explained

'Difficulty with parents, parents complaining about how we'd dealt with the situation, so obviously this child gets the diagnosis that we're not expecting and then he goes away for treatment and erm children were very upset that he wasn't in

school and actually I think the class teacher dealt with it really well. But the parents weren't happy with how it was dealt with, but I think to be honest however it had of been dealt with, there would have been a sector of parents that weren't happy and it was about trying to smooth that over. And because the parents were so agitated it affected the children as well.' (WITH)

The emotional strain of revealing or not revealing, was also illustrated in discussions about 'Should you talk about it?' The participants confirmed that many teachers worry about getting into a difficult topic of conversation, something 'slipping out' or saying anything that might upset the children. Those WITHOUT experience spoke of having a greater awareness of,

'How you talk about the future and health and things that we take for granted'
(WITHOUT)

and others anticipated unease. For example,

'Afterwards you might look back and reflect back on that lesson and think should I have said that? Should I have discussed that?' (WITHOUT)

Some identified that they would look, perhaps hope for, guidance. For example,

'I'd want to know I was doing the right thing, I think the major thing would be reassurance, you know... Should I be talking about it or not? Should I be talking to the child about it?' (WITHOUT)

Those WITH experience illustrated that there were no easy answers to the dilemma. One said,

'Yeah there's fear from teachers, they don't know whether you should mention it or whether you shouldn't' (WITH)

and another added,

'It's also when you're reading stories and the curriculum that you choose, you sometimes find yourself in the middle of a story and think, oh I don't want to see how this ends' (WITH)

Participants, particularly those WITH experience, discussed how 'Should you talk about it?' was directly linked to what parents wanted and how parents were coping. They recounted a number of situations where a child was totally unaware of their condition. For example,

'I've got a child in my class with Cystic Fibrosis; however it's never ever been mentioned in terms of life long illness' (WITH)

They gave examples of children finding out about their condition, not necessarily directly from a teacher, without the consent of parents, and the parents coming back into school extremely angry. One said,

'The difficulty has been with really and the anxiety has been about the parents know about the condition, but haven't shared it with him, or not shared the prognosis and actually yesterday he'd done some googling himself' (WITH)

The participants explained that *not* talking openly about a child with a life limiting or life threatening condition had led to it becoming 'taboo' and an atmosphere of fear among

the school staff who were afraid of saying anything in case of upsetting the parents or the child. Conversely bringing it into the open could be no less challenging for teachers, as one explained,

'I think part of it was parental denial that it was actually going to come to that conclusion at some point. They chose not to tell him, partly they didn't want to say it out loud and partly because they wanted to spare him the worry of it. But dealing with his reaction afterwards and then him openly telling all of the other children was a bit of a shock' (WITH)

The participants WITH experience noted that fears about 'what might happen' could be reduced by good sharing of information among staff and everyone having the 'big picture' Participants WITHOUT experience reflected that once it is out in the open, others in the community could potentially benefit and learn from a child with a life limiting or life threatening condition. As one said,

'Some children who are in these situations are just the most amazing people and what can be brought to school, can be brought to the environment, to the children that they're going to be with is actually a really powerful and a real positive. So although it is very stressful and worrying, you've also got to recognise it can be a very positive lesson for all of us' (WITHOUT)

Sometimes changes in children's appearance, as a consequence of the condition or its treatment, made their health problem all too visible. Participants WITH experience, unlike those WITHOUT, discussed the consequences of having a life limiting or life threatening condition for the child's own emotional and social wellbeing. They spoke of the stigma attached to certain conditions and bullying. One said,

'Then he went off and has chemotherapy and obviously that's quite obvious to everybody, with no hair and he sort of ballooned and looked quite different. And I think there were even some bullying incidents where people didn't understand, so that had to be addressed in terms of explaining to other children why he might look like that' (WITH)

They tried to understand how the other children were feeling.

'There's been a lot of issues with bullying and peer relationships and things like that, erm, which I think is the other children's way of struggling to cope with the fact that this is something they don't see a lot of' (WITH)

They spoke of trying to contain and support the emotions of the other children,

'The other children in the class found it quite difficult, because obviously it was quite a shock when he came in with his treatment; he had a headscarf and so on. So we had to try and prepare the children. That was the harder thing to sort of say, you know, when he comes back he won't look the same, but you need to treat him the same' (WITH)

as well as coping with their own emotions.

'Obviously that was horrific to teachers and people beforehand that had known him' (WITH)

One participant recounted how health professionals in hospital had helped by dressing up a teddy bear with the same wires and medical equipment as the child with the condition. This was brought into the school and allowed the inquisitive children to look, ask questions and understand. On return to school, the child was not stigmatised.

The importance of the school culture and context within which a child with a life limiting or life threatening condition might be, was illustrated by the lack of stigma or bullying reported by the participants WITH experience who had worked in special schools. Where each child had their own difference and needs, and so a child with a condition, did not draw special attention from pupils or staff. For example, one said,

'All the children had special needs and they were all individually different, so it's more accepting and there wasn't any of that [bullying] at all because they just viewed each other as they were and that was that' (WITH)

and another reported,

'I think we tried to have high expectations of all the pupils and therefore a pupil with a life limiting condition wasn't any different to any other pupil' (WITH)

When considering the challenges that teachers face when trying to balance the emotional needs of the child with the condition, their parents, other pupils and their parents, themselves and other staff, it is pertinent to recall the results of the questionnaire shown in Table 8. We have seen that teachers will often turn to the parents for guidance, but find that communication is extremely difficult. More than half of the respondents looked to the pupils themselves to help them to understand the child's non-medical needs. This is within a culture that is very unclear about 'Should you talk about it?' and one that has significant anxieties about how to talk about it within the context of a school that has to meet many demands.

Death and bereavement

The participants' discussions about how teachers cope with the imminent and actual death of a child suggested that their existing anxieties and fears intensified. Those WITHOUT experience described the potential complexities of trying to adequately support others whilst simultaneously grappling with their own understanding and coping with their own emotions. One stated,

'I'd be thinking ... as that illness progresses how I would cope, but also the other students in the class and an understanding that is obviously dependent upon your setting and the students you work with and an understanding that is relevant to them about that other student and what that will look like. It might be their first experience of bereavement; it might be someone they're close to. It might be actually how I would understand that, but also how I would help them to understand that would be really, really challenging' (WITHOUT)

and another reflected,

'I'd be concerned about how I would talk about this to the student and their family. Also with the other students, how I'd integrate them into the class and what I'd need to do to make them feel comfortable and also the other students feel comfortable. How much the other students need to know and what information is vital for everyone to know, other members of staff as well' (WITHOUT)

They had many concerns about what to say, how much to say and how to tell other children. For example one said,

'Depending on what it was, how much it was appropriate for the other children to know, how much they needed to know. How much they would have to know, because of obvious things that they would notice or how much it wasn't really necessary for them to be fully aware' (WITHOUT)

The participants WITH experience confirmed that the anticipated anxieties expressed by those WITHOUT experience were well founded. They described the reality of trying to adequately support others whilst simultaneously grappling with their own understanding and coping with their own emotions. One said,

'It's not going to be easy, but it's how do we help them, obviously without breaking down ourselves' (WITH)

and another explained,

'It's not just his class and his friends, it's also, he's got siblings, so it's them and their friends ...So I think when it does happen it's going to be very, very difficult and it's going to affect the whole school and we haven't got that support. I don't think we're prepared for it, I think it's going to be quite devastating to the staff and probably the children, because it is going to hit them in such a big way in school and also their home environment' (WITH)

The participants WITH experience added another important dimension to understanding the particular emotional needs of teachers coping with a child's death; their own previous experiences of child bereavement. Sometimes participants described a conflict between managing their personal feelings whilst trying to maintain the professional attributes of a teacher. Some found themselves working with a child with the same condition as one who had died. For example,

'I was a bit horrified when I went to one of the schools and they said this child's got cerebral palsy, erm sorry, cystic fibrosis, coz one of my best friends as a teenager died of that whilst I... and that actually had a big impact and I now find myself quite panicky about this child' (WITH)

Another explained that memories from the past were difficult to deal with, but that it is helpful to remember that not all children will have the same outcome. She said she was,

'... aware that these children are different, are being treated and both are actually in remission. So it's very positive, very different outcome to the first child we had with cancer' (WITH)

Those WITH experience discussed floundering and needing support with how to handle bereavement. One expressed her fears about bereavement saying,

'If he was to pass away under our care he would have been a class mate of 28 other 8 year old children. How are we going to, how are we gonna manage that positively and enable the children to, grieve? ... If a child in the class were to die, how do you... I don't think I'd even know where to start with that' (WITH)

Another who had experienced a bereavement, said,

‘When the first child died quite a while ago there was absolutely no support, I was busking it and I felt very vulnerable. The teachers very upset, the parents very upset, obviously devastated. The other children were very upset and I was making it up as I went along and somehow, sort of got most of it right’ (WITH)

The participants spoke of being unable to find free access to guidance about how to share information and to support other children within the school. One had found a source of support, but it was unsatisfactory. She explained,

‘We had a ‘Time to Talk’ counsellor and he wasn’t interested in engaging with anything, so all we could do for a while, was really generic circle times and it felt really pathetic from our side of things, that’s all we could do’ (WITH)

3.3.4 Information and support that teachers would like to have

Participants in the interviews were asked what practices, procedures, resources and people would help teachers, if they were available.

Multi-professional and inter-professional working

Those WITHOUT experience thought that it would be vital to have a meeting with all the professionals involved in the child’s care to ensure that the child got full support, and to make sure that everyone within the school was aware of the child’s needs and his/her care plan.

‘Ideally you’d have a complete professionals’ meeting where you’d have the child’s paediatrician there, the school nurse, everyone who’s going to be involved with that child’s care. Someone representing teachers. Everybody all round one table where you could just sit and say what are you going to do’ (WITHOUT)

Participants WITHOUT experience expected that the health professions would take the lead. They said,

*‘I’d be really surprised if it wasn’t health led, this is a health issue, that’s impacting on education, it’s the health that’s the most important thing here’
(WITHOUT)*

‘I’d see it that I had a responsibility to find out more, to inform members of school, but there must be someone who knows more than me’ (WITHOUT)

and,

*‘It wouldn’t be our responsibility to support the whole family going through that process. We’d play an important role, but we wouldn’t be leading on it’
(WITHOUT)*

Reflecting on their current experiences of communications with health professionals, the participants expressed real concerns about how hard this multi-agency team would be to achieve. One said,

‘I’ve never yet been to any meeting where you have the professionals that you need at that meeting. You never ever get everyone you need at a meeting, and for

someone with significant needs that would be really worrying that you're not going to have the medical people there that you need' (WITHOUT)

Participants WITH experience spoke about professionals from Health and Education needing to work together more effectively around the child, who needed to be in the centre. One explained that when medical professionals and teachers each are focused on their 'own side of the job', the child's needs are not effectively supported. She argued that medical professionals and teachers need to work more efficiently and *overlap* their knowledge.

Quick access to other agencies

'So it's how do you actually have that conversation with the medical professionals? Where you can have that direct access to them' (WITHOUT)

As communication with health professionals was not as efficient or effective as they would like, participants WITH and WITHOUT experience spoke of wanting a contact list of useful agencies that they could turn to, especially when they don't know who is 'out there'. A participant WITH experience said,

'I think probably a list of contact details, so in each local authority or something you've got somebody who is a specialist in students in primary school with cancer, students in secondary school with cancer or multiple sclerosis or something.'
(WITH)

Some participants WITHOUT experience of working with children with a life limiting or life threatening condition said that they would want a 'superfast emergency response team'. They spoke about having a knowledgeable person nearby who could answer teachers' questions and provide reassurance for their worries. One said,

'Someone would be accessible very quickly to come in and help you set up a care plan. Or something in place where you've got that really clear understanding of the condition and knowledge of the child. Ideally perhaps a team of people where you would have that plan set up for that child and have that on-going support'
(WITHOUT)

and another,

'I guess it if it was very serious, you know, that you'd be able to have a direct link to consultants or some communication via the school nurse' (WITHOUT)

They wanted this person to be available to be contacted at short notice,

'Somebody onsite who was confident, knew about the condition, knew about what to do in certain situations. Or somebody who was very nearby that you could contact to give people confidence Probably a health person I would imagine'
(WITHOUT)

or perhaps on the end of a help line.

'... someone you could contact at all times, whether someone specifically for this pupil or some kind of helpline or some emergency contact' (WITHOUT)

A framework for schools to follow

Participants WITH experience of working with a child with a life limiting or life threatening condition wanted a framework to follow. It could be a framework for dealing with health care needs, similar to the Common Assessment Framework; a process to guide the school when making decisions. It could include clarifying issues such as attendance as one explained,

'I feel like we're having to justify things a lot. So when you get an education welfare officer come in, they're looking at your attendance data and then [we're] having to ... almost on the defensive justify what you're doing. Whereas actually you should be praised and supported for the fact that your student is in for 50% of the time, because the decision could be made actually what's the point of education? He's not got long with us, the parents could make that decision ... because there isn't a framework saying what the recommendations and advice should be' (WITH)

Others thought that a framework to support pastoral support was needed. One said,

'That [type of] framework is simply absent for the pastoral side of things, the care side of things. It's the sense that the teacher has to be everything; the carer, the educator, the social worker. But there isn't a framework for it' (WITH)

Support with communication prior to and following bereavement

Participants WITHOUT experience thought that head teachers and teachers would need support with communication prior to and following bereavement. Their suggestions included,

'It would be good to have some way of telling the rest of the class and school, whether that's a DVD for them all to sit down and watch or someone to come in to talk to them. Putting that onus on the class teacher or even on the head teacher to stand up in front of a group of people and explain that condition is not a nice thing to do. So if there was a standardised way of doing that, it may alleviate some pressure' (WITHOUT)

'Getting people from the hospice to come in and talk to people, talk to the children, talk to the staff, talk to the teacher in particular. Because if it's a child that's going to die, as adults we need that support to help' (WITHOUT)

'I think from the children's point of view, we could have had a bit more to really support the children, that's really what we needed' (WITH)

Someone to talk to

Participants WITH and WITHOUT experience spoke about wanting someone to talk to about their worries and concerns, or about matters that they would not want to ask the parents or other teachers. This could be someone unrelated to the situation, or it could be someone who had been through a very similar experience. Typically, they were motivated by not wanting to upset or add burdens to anyone, for example,

'Am I worrying unnecessarily? This is my worry that I don't want to share with anybody in case I'm wrong. You don't want to upset people' (WITH)

Those WITH experience spoke about the illness trajectory, the 'ups and downs' of the child's journey through the illness and how the prognosis could be wrong. They articulated the difficulties of putting 'things in place', 'things constantly changing', and how worrying the uncertainty was. A person to talk to would be helpful, as one said,

'It's having that conversation all the time isn't it. Really, really knowing that you can talk to somebody at any point and you have access or not at any point, and feeling confident that you're going to have that dialogue with people' (WITH)

3.4 Conclusions

The study showed that the most common life limiting or life threatening condition to be reported by the teachers, who were mostly working in mainstream schools in south east England, was cancer followed by cerebral palsy, Duchennes muscular dystrophy and cystic fibrosis. The range included heart conditions, epilepsy, tracheotomy, Downs syndrome, kidney transplant, Alexander's disease and Human Immunodeficiency Virus (HIV). The findings suggest that teachers had some misunderstandings about life limiting or life threatening conditions, in terms of distinguishing them from those that 'threaten life' in the general sense, such as an untreated severe allergy. Some teachers automatically assumed that the child with a life limiting or life threatening condition would only have a very short time to live, which might not be true. There was a wide variance across schools about who is responsible for keeping medical and care needs of pupils updated. About half the teachers in this study had provided medical care for a child. Many teachers were anxious about providing medical care and administering medicines in particular. Some were worried about storage and legal aspects, but many more were anxious about getting it wrong. They wanted more training about administering medication, but made it clear that this would not be enough to allay all their anxieties, because the reality of school life is that the right person might not be immediately available to administer the medication at the time that it is needed.

The findings suggest that teachers often heard about a child with a life limiting or threatening condition from parents, and from that moment, they fully acknowledged the importance of parents and turned to them for guidance. However the parents' own emotional trauma made this vitally important communication extremely difficult. The findings suggest that teachers felt a strong professional responsibility to be informed and to try to find support for themselves and the child. Experience of direct working with such a child increased teachers' awareness of useful sources of information, notably General Practitioners, occupational therapists, physiotherapists and paediatricians. There appeared to be a good awareness of school nurses, but their experiences were mixed. Teachers were concerned about delays in getting what they needed and when they needed it from health care professionals, to a degree that some felt powerless and felt they were failing the children. Teachers turned to the internet for information either because they did not know where else to turn, or because other sources were not providing them with exactly what they need when they need it. Robinson and Summers (2012) found that parents and children want teachers to have a better understanding of children's medical conditions. This study shows that teachers recognise that they need better information and more support in order that the child's medical needs can be better met.

Robinson and Summers (2012) found that children and parents want teachers to provide better educational and emotional support. The teachers in this study wanted educational resources that could provide a structure for their teaching and from which they could

model what to say, what to do to and how to be a really supportive teacher in this difficult situation. They described themselves as floundering at the centre of an emotional web, as they tried to balance the needs of the child with the condition, their parents, other pupils and their parents, themselves and other staff, all within a school culture that could feel insecure and uncertain. Teachers wanted support with the emotional strains that are associated with having a child with a life limiting or life threatening condition in school. They wanted support with understanding how life limiting and life threatening conditions affect children emotionally and behaviourally, and strategies for dealing with the outcomes, and they wanted guidance about how to handle information sharing about the child and the condition with others. In addition to more information, teachers need to be enabled to develop their skills for communicating with other adults and children about serious illness, death and bereavement, and crucially they need emotional support for themselves.

The teachers in this study recognised that school could be an asset to a child and their family by being a place of 'normality' for a child, but a culture of uncertainty is neither normal nor healthy for anyone. Support for teachers to develop their understanding and skills needs to be backed up by a whole school approach to emotional health and wellbeing, which includes addressing bullying and inclusion. The school culture needs to provide psychological security for teachers.

When asked what type of support would help them, teachers sought to bring certainty and clarity to their role. They wanted better information, support and guidance, whether this was from a person, a resource or from a framework. They wanted clarity about school processes and decision making, in respect of issues such as the recording of pupil absences and pastoral support when a child has a life limiting or life threatening condition. They were well aware of the importance of the health and education professionals working together to support the needs of the child, but their experience had taught them that getting everyone together, and getting them to truly integrate their support for a child, was challenging. Some teachers recognised that there were probably local organizations and practitioners about whom they were not aware, and who might be able to provide support, and these could be compiled in a local directory. Some of those without experience of working with a child with a life limiting or life threatening condition assumed that in the event the health professionals would 'take the lead', and wished that there could be a rapid response team with appropriate expertise to help the child. However teachers with experience had more modest aspirations, perhaps recognising that, with the exception of the emergency services, in reality teachers cannot pass the responsibility entirely to another, no matter how much they would like to.

The study showed that teachers who have worked with children with life limiting or life threatening conditions had some knowledge and experience that they might usefully share with those who have not. For example teachers with this experience might be able to share how they managed the school's physical environment, including the storage of medicines; their experience of which types of health care professionals can help with different needs; how to provide flexible and individualised education for the children within the context of schools that are usually focused on academic achievement. They could help teachers to anticipate and prepare for unforeseen emotional and social challenges, including how to work with families, and their experience of how to share information across the school.

Robinson and Summers (2012) found that in order to meet the needs of children with life limiting or life threatening conditions, schools need to recognise that both the medical

model, a focus on the needs arising from the condition, and social models, focussing on the whole school culture and environment, were needed. The teachers in this study were well aware of the medical, emotional and social needs of both the child and the other children and adults that surround that child, as well as the physical attributes of the building and the culture of the school. This study's findings concur with those from the survey reported by the National Foundation for Educational Research (Pyle 2013); teachers need more information, resources and guidance. Teachers need emotional support for themselves if they are to be able to contain their own anxieties and be able to support others, and in turn they need to be supported by a whole school approach to emotional health and wellbeing, which includes addressing bullying and inclusion. Collaboration between themselves and inter-professional health and social care agencies needs to work more effectively.

4. Recommendations

It would be useful to provide schools with:

- Information about where to find accurate, evidence-based, accessible information about the main life limiting or life threatening conditions, common symptoms, behavioural outcomes, sources of specialised expertise and advice about any physical modifications of space that might be required.
- Information about the range of potentially useful health practitioners and the types of knowledge and skills that they have.
- A directory of local/accessible services that can support a child and their family including health care, psychological, voluntary sector and local authority services.
- Ways to improve the quality, and speed of accessing medical information and support for teachers. For example a helpline/dedicated response team for teachers manned by paediatric nurses.
- Educational support related to developing a whole-school approach towards emotional health and wellbeing which would include the school's approach towards dealing with illness, death, bereavement and related issues such as bullying. This would be linked the school's PSHE policy, inclusion policy and the national guidance related to Education, Health and Care plans. It would include the school's processes for pastoral support, attendance issues and staff development.
- Information and practical strategies for handling illness, death, bereavement and related issues within the curriculum.
- Educational support to enhance teachers' emotional literacy skills with particular attention to illness, death, and bereavement.
- Psychological support for school staff e.g. helpline/mentoring/counselling service over and above what is currently offered by teaching unions and professional associations.
- Opportunities to enable teachers who have not had experience of working with children with a life limiting or life threatening condition to talk with those who have.
- Support and training for senior and middle managers to help clarify their roles and responsibilities, and to share best practice.

Wider recommendations:

- To examine the use of the Common Assessment Framework (CAF) and the new Education, Health and Care Plans as means through which children with life limiting or life threatening conditions and their families could be supported; to

understand how the two processes articulate with one another, and to communicate these findings.

- Both the former Labour Government and the Coalition have championed virtual schools and virtual school heads across the country. However, these have predominantly been tasked with providing education for looked after children (LACs) or those who have been excluded. Given the reduction in hospital schools, these virtual schools would appear to provide the ideal means of ensuring that children with life limiting or life threatening conditions, who are often absent from school for extended periods, continue to receive the education they deserve. This would have the additional benefit of ensuring they were not out of synch with their classmates on return to school and provide a way for them to keep in contact with their peers (including other children with a life limiting or life threatening condition). To facilitate this, a mechanism needs to be developed to give children, parents and teachers access to these virtual schools on a flexible and extended basis.

References

Association for Children's Palliative Care (2009) *A Guide to the Development of Children's Palliative Care Services*. 3rd edn. London: ACT (renamed Together for Short Lives)

Children and Families Act (2014), chapter 6, part 5 (100), available at: <http://services.parliament.uk/bills/2013-14/childrenandfamilies.html> (accessed: 4th April 2014).

CLIC Sargent (2012) *No Child with Cancer Left Out. The Impact of Cancer on Children's Primary School Education*. London: CLIC Sargent

Department for Education (2013) *Educating Children with Health Needs*. London: Department for Education

Department for Education/Department of Health (2014) *Special Educational Needs and Disability Code of Practice: 0 to 25 years*. London: Department for Education/Department of Health

Gatta, G., Capocaccia, R., Stiller, C., Kaatsch, PI, Berrino, F., Terenziani, M. and EUROCARE Working Group (2005) Childhood cancer survival trends in Europe: a EUROCARE Working Group Study, *Journal of Clinical Oncology*, 23(16), 3742-3751.

National Collaboration for Integrated Care and Support (2013) *Integrated Care and Support: Our Shared Commitment*. London: Department of Health

Pyle, K. (2013) *NFER Teacher Voice. NFER Teacher Voice Omnibus. March 2013 Survey*. London: CLIC Sargent

Robinson, S. and Summers, K. (2012) An evaluation of the educational support for teachers who teach children with life-limiting illness in schools. *Pastoral Care in Education*, 30 (3) p.191-207

Simmonds, N.J.(2013) Ageing in cystic fibrosis and long term survival. *Paediatric Respiratory Reviews* 14 (1): 6-9

St Leger, P. and Campbell, L. (2008) Evaluation of a school-linked program for children with cancer. *Health Education*, 108(2): 117-129

Appendix 1

The questionnaire

The Teaching for Life (CCCU) project

The Teaching for Life (CCCU) project aims to explore the needs of teachers in relation to working with children with life limiting or life threatening conditions. In the past, these children might have died in early life, but now they are living longer and attending mainstream schools. The outcomes of this exploratory project will be used to develop a larger project, with the intention to produce educational resources and support for teachers. There are no right or wrong answers; we are simply interested in the processes, decisions and perceptions as they occur in your school. PLEASE BE ASSURED THAT YOU OR YOUR SCHOOL WILL NOT BE IDENTIFIED IN THE FINAL REPORT. However, if you do not wish to answer any question, please leave it blank and move on to the next. If you have any questions please contact: sally.robinson@canterbury.ac.uk 01227 782309

Your Role

1. What is your role in your school? *Please tick all which apply*

- Assistant Head Teacher
- Class/Form Teacher
- Deputy Head Teacher
- Head Teacher
- Inclusion Manager
- School Governor
- SENCO
- Teaching Assistant
- Other (please state)

Pupils with life limiting or life threatening conditions

2. Are there currently any pupils with life limiting or life threatening conditions in your school?

- Yes
- No
- Don't know
- Comments

3. If yes, how many pupils are there in your school with life threatening or life limiting conditions and what is the nature of their condition?

4. Have there been any pupils with life limiting illnesses or life threatening conditions in your school in the last 5yrs (excluding any identified in the previous question)? If so, how many pupils have there been and what was the nature of their condition?

5. Do you have direct personal experience of working with a pupil with a life limiting or life threatening condition?

- Yes
- No
- Not Sure

Information, Training and Support

6. How are you made aware of the existence of a pupil with a life limiting or life threatening condition, and their needs, in your school?

7. How often is information about a pupil's medical and care needs updated?

8. Who is responsible for updating information related to a pupil's medical and care needs?

9. Have you ever been involved in providing medical care to a pupil with a life limiting or life threatening condition? *Please tick any which apply*

- No I haven't
- Administering inhalers
- Administering injections
- Administering oral medication
- Administering suppositories
- Changing dressings
- Completing medical records
- Feeding
- Hygiene
- Physiotherapy
- Other/further comments

10. Have you been provided with any formal training about the medical and care needs required by pupils with life limiting or life threatening conditions?

- No
- Yes

If so, please provide details, including the provider, and how often this information is updated. If No, please go to next question.

11. What other sources of information would you consider using to supplement your understanding of the MEDICAL care needs of pupils with life limiting or life threatening conditions? *Please tick all which apply*

- General Practitioner
- Paediatrician
- Parents/Carer
- Occupational Therapist
- Physiotherapist
- SENCO
- Siblings
- School nurse
- Text books
- The pupil themselves
- Websites
- Other (please state)

12. What additional sources of information would you consider using to supplement your understanding of the NON-MEDICAL needs of pupils with life limiting or life threatening conditions? *(E.g. educational, care, support, social, psychological, emotional, spiritual, practical, communication) Please tick all which apply*

- General Practitioner
- Paediatrician
- Parents/Carer
- Occupational Therapist
- Physiotherapist
- SENCO
- Siblings
- School nurse
- Text books
- The pupil themselves
- Websites
- Other (please state)

Support in learning

Please describe any specialist support that is available for pupils with life limiting or life threatening conditions, who may attend your school to enable them to progress academically.

13. Please describe any factors that you would need to take into account when teaching pupils with a life limiting or life threatening condition.

14. Would you or your school employ any specialist teaching techniques or arrangements with these pupils?

15. Is there any additional support that you think would be useful but that you currently do not have access to?

16. Given the nature of this questionnaire, i.e. how a pupil with a life limiting or life threatening condition is supported and taught in schools, please provide any additional comments or information which you feel would be of relevance.

School Characteristics

Please provide information about your school, this will only be used for statistical purposes and to allow the researchers to ascertain if the survey is representative.

17. What phase is your school

- Primary
- Secondary
- Other (please state)

18. What type of school do you work in?

Please tick all which apply

- Academy
- Comprehensive
- High School
- Free School
- Grammar
- Independent
- Special
- State funded (Primary, Junior or Secondary)

- Other (please state)

19. How would you describe the location of your school?

- Rural
- Urban
- Inner City

20. In which region is your school?

- East of England
- East Midlands
- London
- North East
- North West
- South East
- South West
- West Midlands
- Yorkshire & Humberside

Colleagues who work with pupils with life limiting or life threatening conditions

If you know another head teacher, member of a school senior leadership team, teacher, teaching assistant or a member of pastoral staff who works in a mainstream school and who has had experience of working a child with life limiting or life threatening conditions, please could you forward this questionnaire to them, by forwarding your email containing the survey link. Thank you

21. If you are able to pass this questionnaire to a colleague or have received it from a colleague, please provide the name of your school. This information will only be used to help us identify multiple responses from the same school.

22. Case studies

As part of this research Canterbury Christ Church University would value the opportunity to develop case studies of schools with recent experience of pupils with life limiting or life threatening conditions. If you would be prepared to assist in such research please provide your contact details.

Name :

Email :

Phone number:

Thank you for taking the time to complete this questionnaire

A brief summary of the results will be communicated via e mail to all SENCOs who are completing, or have completed, the National Award for Special Educational Needs (SEN) Coordination training at CCCU. If you are not on this list and would like to be sent the summary or have any questions, please contact Dr Sally Robinson sally.robinson@canterbury.ac.uk

Thank you!

Appendix 2

Interview questions

The interviews comprising SENCOs 'WITH' experience were asked:

- Q1 Please could each of you briefly share your experience of working with children with life limiting or life threatening conditions in school.
- Q2 Thinking about these past or current experiences, how does working with a child with life limiting illness affect how you teach?
- Q3 Thinking about your past or current experiences, have you encountered any problems when trying to meet the needs of these pupils? If so, please could you explain?
- Q4 Thinking about your past or current experiences, what current practices, procedures, resources and people are helpful when you are trying to meet the needs of these children? Why? What makes them helpful?
- Q5 What practices, procedures, resources and people would better help you to meet the needs of these children, if they were available? Why?

The interviews comprising SENCOs 'WITHOUT' experience were asked:

- Q1 If I were to inform you that you would be working with a child with a life limiting or life threatening condition in your school, what would you immediately think and feel?
- Q2 What would you do next? What current practices, procedures, resources or people might help you?
- Q3 What additional practices, procedures, resources or people would help you, if they were available? Why?
- Q4 How might working with such a child in your school affect how you teach?

Appendix 3

Medical Glossary

Cancer

Cancer occurs when cells within the body become out of control and multiply, often forming lumps (tumours). The cells are unable to function effectively. When cancer cells break away they spread to other parts of the body forming secondary tumours. The main types of childhood cancer are leukaemias, lymphomas, and brain and spinal tumours.

Cystic fibrosis

Cystic fibrosis is the most common genetically inherited disorder in white people, with a frequency of about 1 in 2500 live births. The genetic defect leads to pathological changes in all organs which contain mucus secreting glands, such as airways and the pancreas.

Life limiting/Life threatening

Life limiting or life threatening conditions arise when some children are born with or who acquire serious medical conditions from which they progressively deteriorate and need increasing care, or conditions for which there is medical treatment, but it might fail. A child may die from these either during their childhood or later.

Organ failure

Organ failure means that there is a failure of an essential system in the body, such as the heart and circulation system or the renal (kidney) system. This is irreversible and can ultimately lead to death.

Human immunodeficiency virus (HIV)

HIV is the causative agent for AIDS. The virus has been found in blood and almost all body fluids, but to date there is evidence that the virus is transmitted only in direct contact with blood or blood products.

Acquired immunodeficiency syndrome (AIDS)

AIDS is characterised by a generalised dysfunction of the immune system. Main causes of transmission result from perinatal transmission and high risk sexual activity.

Duchenne Muscular Dystrophy (DMD)

A neuromuscular disorder which leads to progressive impairment of muscle function, respiratory failure and premature death.

Batten's disease

An inherited disorder of the nervous system that usually manifests itself in childhood. Its early symptoms include vision problems, seizures and in some cases more subtle changes in behaviour or delayed speech. Over time children suffer mental impairment and progressive loss of sight and motor skills. Children become totally disabled and eventually die.

Muscular Dystrophy

Muscular dystrophy is where the muscles of the body get weaker and may slowly stop working.

Cerebral palsy

Cerebral palsy is a condition related to either abnormal brain development or as a result of injury to the brain as it develops. This can occur before, during or after birth, or during early childhood. Cerebral palsy is a disorder that affects muscle tone, movement and motor skills. Cerebral palsy itself is not progressive, so the impairment to the brain does not change, but the effects on the body may change over time for better or worse.

Mucopolysaccharidosis

Mucopolysaccharidosis is a condition where children are unable to produce one of the essential enzymes which replace used materials in the body and break them down for disposal. Infants and very young children may show no sign of the disease but as more and more cells become damaged by the storage of used material, symptoms begin to appear. The condition, for which there is no cure, continues to worsen, affecting bones, tissues, organs and nerves and causing pain.

Brain and spine injuries

Brain and spine injuries are one of the leading causes of acquired disability and death in children and young people. They are most commonly caused by trauma from falls and traffic accidents.

Asthma

An obstructive disease of the airways characterised by reversible hyperactivity of the bronchi and trachea to a variety of stimuli.

Diabetes

A disorder of metabolism caused by a deficiency of the hormone insulin.

Epilepsy

A term used to classify a group of neurological disorders affecting the brain resulting in seizure activity.

Tracheostomy

Tracheostomy is a surgical opening in the trachea between the second and fourth trachea rings. It is usually formed in children who have problems with upper airway obstruction, infectious conditions and to provide airway support for long term ventilation

Downs Syndrome

Downs syndrome is the most common chromosomal abnormality attributable to an extra chromosome 21.

Haemophilia

A genetic condition which affects the clotting of the blood.

Alexander's disease

A progressive neurodegenerative disease.

Spina bifida

Spina bifida is associated with an abnormality of the neural tube closure in embryo. Defects associated with neural tube closure make up the largest group of conditions associated with congenital anomalies.

Allergy

Allergies are caused by allergens or allergic antigens that are capable of inducing Immunoglobulin E antibody formation when ingested, injected or inhaled.

Lupus erythematosus (LE)

LE is a chronic inflammatory disease of the collagen or supporting tissues of the body. It follows a course of remissions and relapses. As connective tissue is found everywhere within the body, almost all organs or structures can be affected.

Myasthenia Gravis

A neuromuscular disease leading to muscle weakness.

Hip dysplasia (congenital)

An imperfect development of the hip that can affect the femoral head which affects long term mobility.

Neuropathy

A disorder affecting peripheral nerves resulting in long term nerve damage. Neuropathies are caused by a number of hereditary diseases, traumatic injuries and metabolic conditions.

Neurofibromatosis

A congenital skin disorder which eventually results in peripheral nerve damage.

Trachobonchomalasia

A condition which eventually leads to softening of the tracheal and bronchial cartilage affecting the efficiency of the respiration system.

Diamond blackfananaemia

A disorder of the bone marrow which may result in myelodysplastic anaemia in which immature red blood cells are produced affecting the delivery of oxygen around the body physiological systems.

Robinows syndrome

A rare disorder of the skeletal system affecting growth and development

Russell-Silver syndrome

A congenital condition resulting in poor growth and development.

Osteogeneses imperfecta

An inherited condition characterised by brittle bones which are easily fractured.

Inhaler

A hand-held device which delivers medication via the inhaled route.

Suppository

A form of medication which can be administered by the rectal route. It is mainly used when the oral route is difficult or contraindicated.

References

Wong. L. Donna and Wilson David (1995) Whaley and Wong's nursing care of infants and children. 5th edition. Mosby in St Louis.

Appendix 4

Educational Glossary

SEN

Special Educational Needs

SENCO

Special Educational Needs Coordinator

STS

School Travel Service

PSHE

Personal Social Health Education

ISBN 978-1-909067-48-6