Educating Children with Life Limiting and Life Threatening Conditions

Sally Robinson  Faculty of Health & Wellbeing

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49,000 children and young people (0-18) in the UK are diagnosed with a life limiting or life threatening condition (Fraser et al. 2011). Many are in mainstream schools.
Definitions

**Life-threatening** - curative treatment exists, but might fail cancer, organ failure, HIV/AIDS

**Life-limiting** – no reasonable hope of cure

cystic fibrosis, Duchenne muscular dystrophy, Battens disease, severe cerebral palsy, severe neurological disabilities e.g. spine/brain injuries

Association for Children’s Palliative Care, 2009)
Support for teachers who teach children with life limiting illness in mainstream schools

Sally Robinson and Kathryn Summers
<table>
<thead>
<tr>
<th>Life limiting/threatening</th>
<th>Not life limiting/threatening</th>
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<tbody>
<tr>
<td>Brain tumour survivors</td>
<td>Chronic disease (not specified)</td>
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<td>Cancer</td>
<td>Chronic fatigue syndrome</td>
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<td>Cancer survivors</td>
<td>Chronic illness (not specified)</td>
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<tr>
<td>Cerebral palsy</td>
<td>Chronic illness (asthma, diabetes, obesity)</td>
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<td>Cerebral palsy and other disabilities</td>
<td>Chronic illness/disability</td>
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<td>Chronic illness (usually cancer)</td>
<td>Chronic pain</td>
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<td>Chronic or life threatening disease</td>
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<td>Cystic fibrosis</td>
<td>Diabetes type 1</td>
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<td>HIV</td>
<td>Epilepsy and diabetes</td>
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<td>Juvenile idiopathic arthritis</td>
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<td>Leukaemia</td>
<td>Sickle cell disease/disorder</td>
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<td>Life threatening illness</td>
<td>Speech and physical disabilities</td>
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<td>Life-limiting or life threatening conditions</td>
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54 papers

23 papers
“I don’t think the school wanted to waste their money on GCSEs for me because they thought I was going to fail.”

(Ricky, diagnosed with leukaemia, age 15)
Conclusions

• Children’s needs not being well met.
• Their condition and their symptoms impact on their (i) learning (ii) self esteem and (iii) peer relationships
• The children and their families feel under supported by schools.
• We found no research about teachers’ views or experiences of working with children with a life limiting or life threatening condition.
Teaching for Life

Dr Sally Robinson (Public Health)
Kathryn Summers (Child Nursing)
Dr Alison Ekins (Special Educational Needs)
Ian Durrant (Education)

2013
Teaching for Life

AIMS
To explore the needs of teachers in relation to working with children with life limiting or life threatening conditions
Methods

On-line questionnaire

550 teachers undertaking S.E.N. + snowball to staff in mainstream schools who had experience of working with children with life limiting or life threatening conditions.

90 questionnaires returned. Response rate 16.4%.
## Interviews \((n=13)\)

<table>
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<tr>
<th>Number of participants per interview</th>
<th>Type of school (participants)</th>
<th>Participants</th>
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<tr>
<td><strong>WITH</strong></td>
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<td>Primary (2) Secondary academy (1)</td>
<td>SENCOs who were undertaking training</td>
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<td>3</td>
<td>Primary (3)</td>
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<td>4</td>
<td>Primary (3) Secondary (1)</td>
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<td>Infant (1)</td>
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<td>Primary (2) Primary academy (1) Secondary grant maintained (1) Secondary (1)</td>
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<tr>
<td>3</td>
<td>Primary (1) Secondary (1) Special (1)</td>
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<td>6</td>
<td>Special school (4 teachers, 1 link practitioner, 1 therapy assistant)</td>
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<tr>
<td><strong>WITHOUT</strong></td>
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<td>2</td>
<td>Primary (2)</td>
<td>SENCOs who were undertaking training</td>
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<td>4</td>
<td>Infant/nursery (1) Primary/nursery (2) Secondary academy (1)</td>
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<td>Primary (3) Secondary (1)</td>
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<tr>
<td>4</td>
<td>Primary (2) Junior (1) Secondary (1)</td>
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Teachers delivering medical care

Half of the teachers had delivered medical care for a child. High levels of anxiety.

‘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)
Teachers delivering medical care

Practicalities

‘If you’re the class teacher, 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)
Sources of information and support for teachers

- Parents
- Child
- Healthcare professionals
- Web sites
Educational challenges

‘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.’
Emotional challenges
Emotional challenges

‘Are your ‘needing to know parents’ via a letter, text or e mail, 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)
Emotional challenges

‘Yeah there’s fear from teachers, they don’t know whether you should mention it or whether you shouldn’t.’  (WITHOUT)
Emotional challenges

‘I’ve got a child in my class with Cystic Fibrosis; however it’s never been mentioned in terms of life long illness.’ (WITH)
‘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)
Emotional challenges

‘I think part of it was parental denial that 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)
Emotional challenges

‘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)
Emotional challenges

‘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 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)
Emotional challenges

‘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.’
Emotional challenges

‘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. (WITH)
Emotional challenges

‘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)
Emotional challenges

‘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)
Recommendations

Teachers want ...

• Information on medical conditions
• Information on health practitioners
• Directory of services
• Quick access to medical information
• Practical strategies for handling illness, death, bereavement within the curriculum
• Support with developing emotional literacy skills
Recommendations
Teachers want ...

• Whole school approach to emotional health and wellbeing
• Psychological support for school staff
• Support and training for senior and middle managers
• Those ‘with’ experience need to share those ‘without’.
Children and Families Act 2014

Special educational needs and disability code of practice: 0 to 25 years
Statutory guidance for organisations which work with and support children and young people who have special educational needs or disabilities

January 2015

Supporting pupils at school with medical conditions
Statutory guidance for governing bodies of maintained schools and proprietors of academies in England

April 2014

National Framework for Children and Young People’s Continuing Care

2016

Emerging Framework

2016

Integrated Personal Commissioning

Cantebury Christ Church University
In this chapter we:

- ...
- ...
- ...

Introduction

Our Teaching for Life findings

Policy review

Practical considerations

Practical resources

Reflective activities
Chapter 1: Teaching children with life-limiting or life-threatening conditions: understanding the issues

Chapter 2: Understanding and responding to the policy context

Chapter 3: Understanding life-limiting and life-threatening conditions

Chapter 4: Medical treatment and health care practices in school

Chapter 5: Communicating with the child and their family

Chapter 6: Communicating with other professionals: working collaboratively

Chapter 7: Communicating and sharing information with others

Chapter 8: Teaching and learning approaches

Chapter 9: Understanding and supporting emotional and behavioural changes

Chapter 10: Whole school policies

Chapter 11: Whole school culture

Additional resources:  Glossary
Useful contacts

References
Accessible, Informative, Useful

**Accessible**: tried not to assume prior knowledge

- Medical terms for non medics
- Educational terms/policy for non Teacher

**Informative**: Medical, legal, ethical, social

**Useful**: A handbook that could be used by schools, medics, parents, families.
eResources – sources of information

1 Useful web sites

The Children's Cancer and Leukaemia Group (CCLG) publishes a range of very useful publications which will explain a range of issues relating to cancer and leukaemia. They can be accessed at http://www.cclg.org.uk/Publications/All-publications.

West Midlands Paediatric Palliative Care Network (2016): West Midlands Children and Young People’s Palliative Care Toolkit: http://www.togetherforshortlives.org.uk/professionals/externalresources/2918westmidlandsToolkit

Children with Cancer UK/Resources: http://www.childrenwithcancer.org.uk/resources


Education matters.org/site/DocSet

3 Resources for teachers to use with children in class

Practical resources

Activity books for primary school

Books for secondary school

1 Children’s books about experiencing illness, death and bereavement

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<thead>
<tr>
<th>Author</th>
<th>Title</th>
<th>Subtitle/Notes</th>
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<tr>
<td>Bickford-Smith, C.</td>
<td>The Fox and the Star</td>
<td>London: Particular Books</td>
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<tr>
<td>Crossley, D.</td>
<td>Muddles, Puddles and Sunshine: Your Activity Book to Help When Someone Had Died (Early Years). Stroud: Hawthorn.</td>
<td>Activities for children to remember a loved one</td>
</tr>
<tr>
<td>Rosen, M.</td>
<td>Michael Rosen’s Sad Book. London: Walker Books.</td>
<td>A book that acknowledges the feelings of sadness</td>
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</table>
2 Model process for developing individual health care plans (DfE, 2015)

- Parent or health care professional informs school that child has been newly diagnosed, or is due to attend a school, or is due to return to school after a long-term absence or that needs have changed.

- Headteacher or senior member of school staff to whom this has been delegated coordinates meeting to discuss child's medical support needs and identifies member of school staff who will provide support.

- Meeting to discuss and agree on need for Individual Health Care Plan to include key school staff, child, parent, relevant health care professional and other medical/health clinicians as appropriate (or to consider written evidence provided by them).

- Develop individual health care plan in partnership - agree who leads on writing it. Input from health care professional must be provided.

- School staff training needs identified.

- Health care professional commissions/delivers training and staff signed off as competent review date agreed.

- Individual health care plan implemented and circulated to all relevant staff.

- Individual health care plan reviewed annually or when condition changes. Parent or health care professional to initiate.

1 Flowchart of when and how to share information

- You are asked to share information. Is there a clear and legitimate purpose for sharing information?
  - Yes
  - No

- Does the information enable an individual to be identified?
  - Yes
  - No

- Is this information confidential?
  - Yes
  - No

- Do you have consent?
  - Yes
  - No

- Is there another reason to share information such as to fulfil a public function or to protect the vital interests of the information subject?
  - Yes
  - No

- You can share?
  - Yes
  - No

- Share Information:
  - Identify how much information to share.
  - Distinguish fact from opinion.
  - Ensure you are giving the right information to the right individual.
  - Ensure, where possible, that you are sharing the information securely.
  - Inform the individual that the information has been shared if they were not aware of this as long as this would not create or increase risk of harm.

- Record the information-sharing decisions and your reasons in line with your organisation or local procedures.

- If there are concerns that a child is suffering or likely to suffer harm, then follow the relevant procedures without delay. Seek advice if unsure what to do at any stage and ensure that the outcome of the discussion is recorded.
1 Example letter inviting parents to contribute to the development of an individual health care plan for their child

Dear Parent,

Developing an individual health care plan for your child

Thank you for informing us of your child's medical condition; enclose a copy of the school's policy for supporting pupils with medical conditions for your information.

A central requirement of the policy is for an individual health care plan to be prepared, setting out what support each pupil needs and how this will be provided. Individual health care plans are developed in partnership between the school, parents, pupils and the relevant health care professional who can advise on your child's case. The aims to ensure that we know how to do this, with the aim of fulfilling fully in school condition.

A meeting has been arranged for the school to discuss the plan with you and other family members.

If you have any questions or concerns, please do not hesitate to contact me.

Yours sincerely,

[Signature]

2 Example of a risk assessment form

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<th>ASSESSMENT NO.:</th>
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<tr>
<td>Assessed by (Name):</td>
<td>DEPARTMENT code:</td>
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<tr>
<td>NATURE OF ACTIVITY:</td>
<td>Health &amp; Safety Risk Assessment</td>
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<tr>
<td>LOCATION:</td>
<td>REVIEW DATE:</td>
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<tr>
<th>Hazard</th>
<th>Persons at Risk</th>
<th>Current Control Measures</th>
<th>Severity (S)</th>
<th>Likelihood (L)</th>
<th>Risk Rating (S x L)</th>
<th>Additional Control Measures Required</th>
<th>Revised Risk Rating</th>
<th>Action Sign Off Date/ Reasonable Person</th>
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3 Parental agreement for setting to administer medicine (DfE, 2014)

The school/setting will not give your child medicine unless you complete and sign this form and the school or setting has a policy that the staff can administer medicine.

Date for review to be initiated by

Name of school/setting

Name of child

Date of birth

Group/class/form

[Signature]

4 Parental agreement for setting to administer medicine (DfE, 2014)

The school/setting will not give your child medicine unless you complete and sign this form and the school or setting has a policy that the staff can administer medicine.

Date for review to be initiated by

Name of school/setting

Name of child

Date of birth

Group/class/form

[Signature]

[Agreed member of staff]
2 Class activities for children who have suffered a loss or bereavement

The following ideas for supporting children about loss and bereavement are based on Sunderland (2003b). Her book contains photocopyable resources.

Remember that it feels much safer for children, younger and older, to consider the feelings of a character or an animal. It can feel too threatening to be asked to directly communicate about themselves. Working with metaphors is enough; teachers should not feel that they need to explain the metaphor. The teacher needs to be guided by the children about whether they are able to use ‘you’ and ‘name of child’ OR use a metaphor.

Present a simple story, in pictures or words, of two characters who are friends. Then one dies and one is left alone. What happens to him? Draw, paint, write, talk or show (movement or miniatures) what happens to him. Create music to hear how he feels at the time of loss and how he feels later.

Provide a picture of a deserted place. It could be an empty building, an empty playground, an empty field. Ask, ‘What does the world feel like when you’ve lost someone or something very precious?’ Draw, paint, write, talk or show (movement or miniatures) how it feels. Using music, what does it sound like?’

Read a story in which a character suffers a loss. Draw, paint, write, talk or show (using miniatures) what life was like for a character ‘before’ and ‘after’ a loss. Make music to hear how it sounded before and how it sounds after.

How did it feel when the character found out? List a range of potential feelings, possibly with pictures, and allow children to tick which applied to them and discuss in a small group. Draw, paint, write, talk or show (using movement or miniatures) how it felt. Make music to hear how it sounded.

How does it feel now? Draw, paint, write, talk or show how it feels now. Create music to show how it feels now.

Similarly, questions could include feelings about:
- the first time ‘the village’ knew that their pet dog was going to die
- how it felt the last time ‘the village’ were with the pet dog
- the squirrel was missing her friend too much. Draw, paint, talk or show how it feels to miss someone too much. What does it feel like in her head? What does her heart look like? How does it feel inside her body? What does the world feel like?
- If the squirrel’s much-missed friend was:
  - a colour, what colour would he be?
  - an animal, what animal would he be?
  - a food, what food would he be?
  - a place, where would he be?
  - a musical sound, what sound would he be?

3 Mindfulness exercises

These can be used by staff, children, parents and families. They are a way to relieve stress and anxiety and centre yourself. The aim is to focus on the moment rather than reliving the past or worrying about the future. It is also a way to see the everyday in a new way, to appreciate the beauty of objects, events and people and how fortunate we are. As such, they are techniques to deal with current anxiety and to build future resilience.

Living Well provides a number of mindfulness exercises which can be downloaded at https://www.livingwell.org.au/mindfulness-exercises-3 (accessed 4/11/16).


Pocket Mindfulness at http://www.pocketmindfulness.com/6-mindfulness-exercises-you-can-try-today (accessed 4/11/16) provides six exercises that anyone can use:

1 Mindful breathing

Stand, sit or lie down. Breathe slowly and then deeply in through your nose and out through your mouth. Let go of your thoughts by focusing on your breathing. Think about the air entering and leaving your body. This is the basis of meditation.

2 Mindful observation

Pick an object in the natural environment and focus on it for a minute or two. Notice its structure and form. Allow yourself to appreciate its elements and connection with nature.

3 Mindful awareness

Focus on an everyday object or action, for example, opening a door, reading a book. Take the time to connect with the object, its texture, construction, form. Try to appreciate how lucky you are to have these senses but also this rich variety of objects.

4 Mindful listening

Select some music you have never heard before and listen to it with your eyes closed or in a darkened room. Try to focus on the journey it is taking you on. Let the music fill your mind to the exclusion of all else.

5 Mindful immersion

When engaging in an everyday activity, like cooking or decorating - or, for children, draw-
Discussion

Please take a moment to examine the resources

• Understanding condition
• Communicating
• Teaching
• Developing policies

• How might you use them?
• What additional support might you/ families/ children need?
• Where next for work in this area?
Questions, Comments, Concerns
Thank you for listening

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