

Educating Children with Life Limiting and Life Threatening Conditions

Sally Robinson Faculty of Health & Wellbeing

Ian Durrant Faculty of Education



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, Batters disease, severe cerebral palsy, severe neurological disabilities e.g. spine/brain injuries

Support for teachers who teach children with life limiting illness in mainstream schools

Sally Robinson and Kathryn Summers

Life limiting/threatening **54 papers** **Not life limiting/threatening**

Brain tumour survivors
Cancer
Cancer survivors
Cerebral palsy
Cerebral palsy and other disabilities
Chronic illness (usually cancer)
Chronic or life threatening disease
Cystic fibrosis
HIV
HIV/AIDS
Leukaemia
Life threatening illness
Life-limiting or life threatening conditions

23 papers

Chronic disease (not specified)
Chronic fatigue syndrome
Chronic illness (not specified)
Chronic illness (asthma, diabetes, obesity)
Chronic illness/disability
Chronic pain
Diabetes type 1
Epilepsy and diabetes
Juvenile idiopathic arthritis
Sickle cell disease/disorder
Speech and physical disabilities



“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%.

	Respondents' roles (<i>n=90</i>)	WITH (<i>n=53</i>)	WITHOUT (<i>n=37</i>)
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

Interviews (n=13)

	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)	

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.'

(WITHOUT)

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)

Emotional challenges

‘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.' (WITHOUT)

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'.

Teaching for Life

Full Report



Durrant, Robinson, Ekins,
Summers and Jones, 2014



Children and Families Act 2014


Department
for Education


Department
of Health

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


Department
for Education

Supporting pupils at school with medical conditions

Statutory guidance for governing bodies
of maintained schools and proprietors of
academies in England

April 2014


Department
of Health

National Framework for Children and Young People's Continuing Care

2016

January 2016


Local
Government
Association


NHS
England

2016



Integrated Personal
Commissioning

Emerging Framework




Canterbury
Christ Church
University



Educating Children with Life-Limiting Conditions



A practical handbook for teachers, children and their families

Alison Ekins, Sally Robinson, Ian Durrant and Kathryn Summers

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

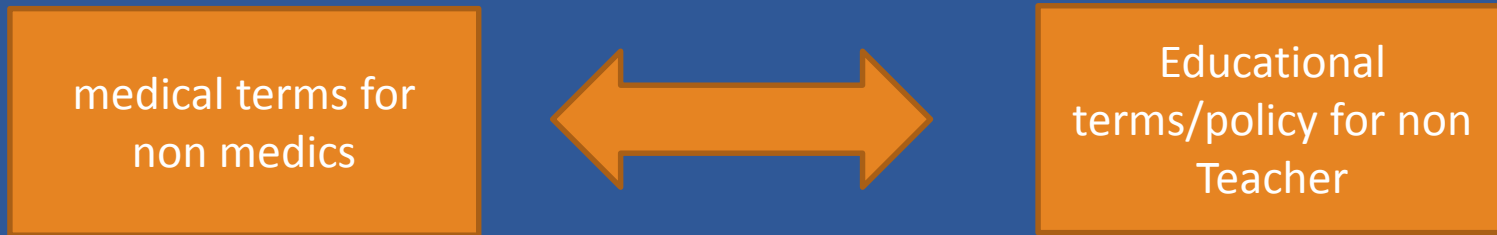
Additional resources: Glossary

Useful contacts

References

Accessible, Informative, Useful

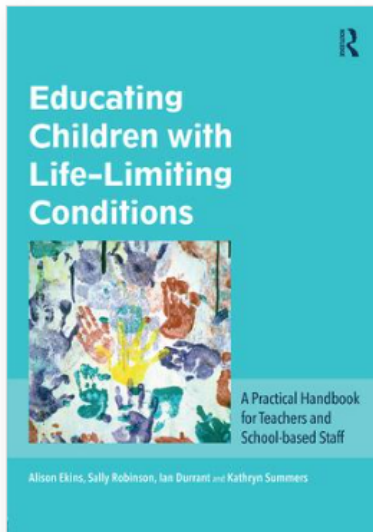
Accessible: tried not to assume prior knowledge



Informative: Medical, legal, ethical, social

Useful: A handbook that could be used by schools, medics, parents, families.

eResources



Educating Children with Life-Limiting Conditions

A Practical Handbook for Teachers and School-based Staff

By **Alison Ekins, Sally Robinson, Ian Durrant, Kathryn Summers**

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eResources

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>

Resources to help students, parents and teachers manage cystic fibrosis in the classroom: Living with CF, CF and School (Cystic Fibrosis Foundation, 2016): <https://www.cff.org/Living-with-CF/CF-and-School/>

Education matters
org/site/DocSe



3 Resources for teachers to use with children in class

Practical resources

Child Bereavement UK (2014) *Conversations about Loss and Change*. Northampton: Fink Cards
Free Spirit Publishing (2008) *Feelings in a Jar*
Wilson, P. and Long, I. (illustrator) (2008) *Feelings Blob Cards (Blobs)*. Brackley: Speechmark

Activity books for primary school

Crossley, D. (2000) *Muddles, Puddles and Sunshine: Your Activity Book to Help When Someone Has Died*. Stroud: Hawthorn Press
Heegaard, M. (1992) *Facilitator Guide for Drawing Out Feelings*. Chapmanville, WV: Woodland Press
Heegaard, M. (1991) *When Someone Has a Very Serious Illness: Children Can Learn to Cope with Loss and Change (Drawing Out Feelings)*. Chapmanville, WV: Woodland Press
Heegaard, M. (1991) *When Someone Very Special Dies: Children Can Learn to Cope with Grief (Drawing Out Feelings)*. Chapmanville, WV: Woodland Press
Heegaard, M. (1991) *When Something Terrible Happens: Children Can Learn to Cope with Grief (Drawing Out Feelings)*. Chapmanville, WV: Woodland Press
Wilson, P. (2009) *Big Book of Blob Trees (Blobs)*. Brackley: Speechmark

Books for secondary school

Grollman, E. A. (1999) *Straight Talk about Death for Teenagers: How to Cope with Losing Someone You Love*. Saint Louis: Turtleback Books



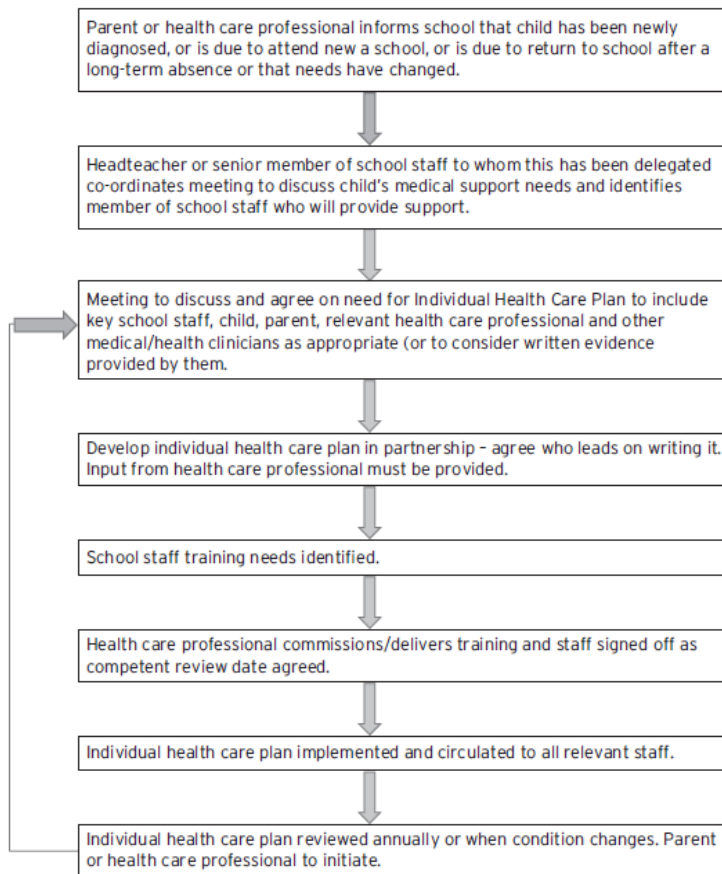
1 Children's books about experiencing illness, death and bereavement

Bickford-Smith, C. (2015) <i>The Fox and the Star</i> . London: Particular Books. Loss and learning to accept change
Brown, L. K. and Brown, M. (1998) <i>When Dinosaurs Die: A Guide to Understanding Death</i> . New York: Little Brown Books for Young Readers/Hachette Book Group. Explores lots of reasons people die
Crossley, D. (2000) <i>Muddles, Puddles and Sunshine: Your Activity Book to Help When Someone Has Died (Early Years)</i> . Stroud: Hawthorn. Activities for children to remember a loved one
Durrant, A. (2013) <i>Always and Forever</i> . London: Picture Corgi, Random House. Bereavement, loss and grief
Heegaard, M. (2003) <i>Living Well with My Serious Illness</i> . Manhattan: Taylor Trade. An activity book
Jeffers, O. (2010) <i>The Heart in the Bottle</i> . London: Harper Collins. A book about loss and grief
Rosen, M. (2011) <i>Michael Rosen's Sad Book</i> . London: Walker Books. A book that acknowledges the feelings of sadness
Schulz, C. M. (2002) <i>Why, Charlie Brown, Why? A Story about What Happens When a Friend Is Very Ill</i> . London: Ballantine Books, Random House.
Stickney, D. (1997) <i>Waterbugs and Dragonflies: Explaining Death to Young Children</i> . London: Bloomsbury Continuum.
Stokes, J. (2009) <i>The Secret C: Straight Talking about Cancer</i> . 2nd edn. Cheltenham: Winston's Wish. Explains cancer to children
Sunderland, M. (2003) <i>The Day the Sea Went Out and Never Came Back (Helping Children with Feelings)</i> . London: Speechmark. A book about the feelings of loss
Wagner, J. (1980) <i>John Brown, Rose and the Midnight Cat</i> . London: Puffin/Penguin Books. Learning to accept change

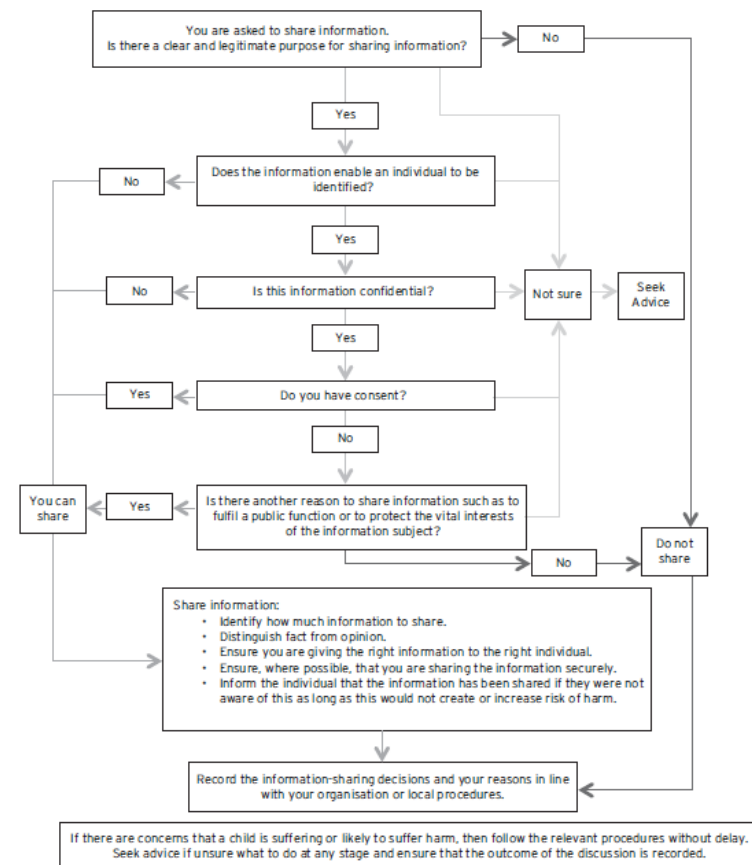
eResources – checklists/models



2 Model process for developing individual health care plans (DfE, 2015)



1 Flowchart of when and how to share information



eResources – forms/exemplars

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. I enclose a copy of the school's policy for supporting pupils at school 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 aim is to ensure that we know how to support your child effectively and to create clarity about what needs to be

done, who the major judgements fully in school condition.

A meeting been scheduled you could people. Please care professional at the meeting.

If you are health care at the support] would be

Yours sincerely

2 Example of a risk assessment form

Date of Assessment:		ASSESSMENT NO:
Assessed by (Name):		DEPARTMENT code:
NATURE OF ACTIVITY:	Health & Safety Risk Assessment	DATE OF ACTIVITY:
LOCATION:		REVIEW DATE:

Hazard	Persons at Risk	Current Control Measures	Severity (S)	Likelihood (L)	Risk Rating (S x L)	Additional Control Measures Required	Revised Risk Rating	Action Sign Off Date/ Responsible Person

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

Container as dispensed by the pharmacy.

[agreed member of staff]

My knowledge, accurate at the time of writing, and I give consent to school/setting in accordance with the school/setting policy. I will inform the school/setting immediately if the dosage or frequency of the medication or if the medicine is stopped.

Date _____

eResources – practical exercise



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 photocopiable 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, what place 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).

NHS Choices also provides information and tips about how to deal with stress and anxiety through mindfulness at <http://www.nhs.uk/Conditions/stress-anxiety-depression/Pages/mindfulness.aspx> (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

Dr Sally Robinson

sally.robinson@cantebury.ac.uk

Ian Durrant

ian.Durrant@cantebury.ac.uk

