



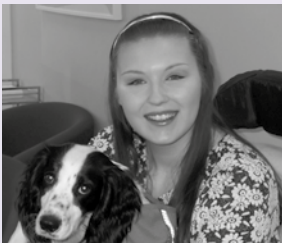
Difficult Conversations

Making it easier to talk about end of life issues with young adults with life-limiting conditions.



Foreword

Why do we wait until we're dying to think about our plans for the end of our lives? If we all had a plan drawn up - which we can change at any time - we could get on with life knowing that our final wishes have been thought about, discussed and put down in writing. Doing my own end of life planning was difficult, but it gave me a feeling of relief when it was completed. Unfortunately there is no given way to broach the conversation; you have to get a feel for the person and the family before you can gauge the approach to take. You must go in with an open mind and listen to the individual and respond appropriately. It's a difficult conversation - as the title says - so each different person will have a different outlook on life, different wishes and different reactions, and need a unique approach. Professionals need to get to know the person first and to build up the trust before you can jump in and start talking about end of life care. Having a bond with and trust in the person you are telling your intimate wishes to is so important. I am fortunate; it was my hospice nurse of three years who helped me to do my plan, with my mum present as I requested, and we have such a good bond. I feel comfortable with her and that is essential. She led the conversation in a way that was sympathetic, unbiased and attentive. She let me talk as much or as little as I wanted and put as much of what I said into my end of life plan as possible. I have no problem talking about my mortality, but not everyone shares my ability and comfort in talking about the end of their life. Be calm, compassionate and put the person at the centre of the conversation. It's their life, and their death, after all.



Lucy Watts

Lucy Watts
Young adult with a life-limiting condition

About this guide

This guide was developed in response to a gap in health professionals' skills in having difficult conversations with the growing number of young adults* with life-limiting conditions who come in to their care. This gap was one of the findings of the STEPP research project (a project which looked at examples of positive practice in transition to adult health settings for young adults with life-limiting conditions).

It aims to support professionals to improve quality of life and provide peace of mind for young people and their families, by sharing insights from young people themselves and their families about discussing the end of life. The guide describes feelings they experience when having conversations on this sensitive subject and gives ideas about how to approach it. It also aims to be a useful prompt that young people can use to broach the subject of end of life planning with family, friends and professionals.

As you read the pages that follow, you will see that the overwhelming message from the young adults and parents we spoke to was 'we want to focus on living, not dying'. Whilst this guide is not representative of all young adults and their families, it shares ideas about how it might be possible to sensitively and appropriately integrate openness about dying into the lives of those who have a zest for life. This openness can provide a young adult with the opportunity to have an honest conversation about their wishes for their future care and how they wish to be remembered, bringing peace of mind to both them and their family.

We recognise that conversations between professionals and parents of young adults with life-limiting conditions also have their challenges. We have not focussed on this in this guide but have signposted to resources that may be helpful.

We hope the strength of feeling and urgency conveyed in these conversations is reflected in the style of writing and presentation.

*We use the terms young adults and young people interchangeably throughout the guide.

Learning from what we didn't hear

To produce this booklet, we spoke to 13 young adults with a life-limiting condition and families who had cared for a young person in the past. As with other guides in the series, we wanted to hear young people's perspectives on whether they found it helpful to be open about dying, death and bereavement and if they had found these conversations helpful, what had made them that little bit easier. We were as always open to the possibility that the answer might be 'we don't want to talk about it'. We did struggle to find young people who felt comfortable talking about their end of life and the overriding message was that young adults want to focus on living, not dying. This key message was reinforced in the conversations that we had. Young people want to live life to the full in the limited and unpredictable time that they have. They want to achieve personal and professional goals in life. Their insights and messages resonated common themes which we share with you below.

However they did also recognise that alongside this there are times when it is not only necessary but helpful to talk about issues to do with dying.

This guide sets out some of the key messages and direct quotes from young people and parents that we talked with. We hope that it will give you the confidence to take the opportunity to have these difficult, but essential, conversations.



We want to live now

"It's going to happen so you have to deal with it. It's going to happen to everyone."

Young adults may have short lives but they want to **LIVE now**. There is so much for them to achieve, so many dreams, hopes and ambitions and all to fit into a short life span.

Having an end of life conversation may be needed, yes, but have it and then allow them to get on with living.

It can be too overwhelming to talk and think of dying all the time. Of course they may need to talk about these things in the future as things change in order to enable them to have a better quality of life, but the desired focus is more on living than dying.

These young adults may need help and support, like a team of people around them to help them achieve their goals who know them and respect their wishes.

They may need emotional support too to help them work through difficult feelings like anger and sadness about things they may not achieve in their lives. It is also useful for them to connect with their peers socially but mostly they want you to listen to them and help them to get on with **living!**

"WHEN THE CONDITION PROGRESSES, PEOPLE START SAYING THAT YOU SHOULDN'T DO THIS OR THAT, BUT I DISAGREE."

"We need support to be able to live."

"KNOWING THAT I WON'T LIVE AS LONG AS OTHER PEOPLE, MAKES ME LIVE MORE AND MAKE THE MOST OF EVERY DAY. I'VE GOT TO MAKE SURE EVERY DAY IS WORTH IT."

"I seem to go through cycles where I'm determined and nothing's going to stop me and at other times I'm angry and upset about all the things I will miss out on."

"I don't want to dwell on death, because you can achieve so much in a short life."

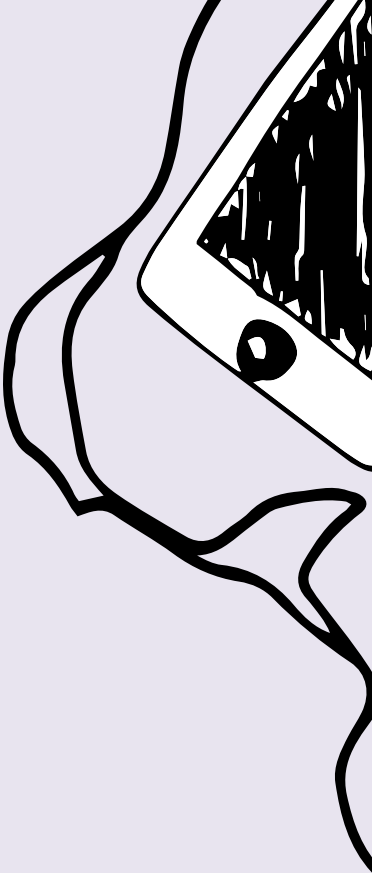
But when they do need to talk about it:

Think about them

Young adults may have a range of complex needs. They are young and in an ideal world would be looking forward to a long and fulfilling life, not thinking about their final days. As they get older they deal differently with the information they receive: at a young age it is overwhelming, but as they get older most young adults like to know what is happening so that they can plan and be in control of their future. They need trusted people around them who know them, listen to them, support them and will carry out their wishes. This is of great importance, giving them peace of mind that their last days and after will be as they wished for.

Before a conversation

- Find out who they are. Get to know and understand them, the people and things that matter to them.
- Build a trusted relationship with them.



“I’m not sure there is a given way to approach it – we’re all different, having different outlooks, different feelings and understanding of our conditions. No two of us are the same – but I’d want them to talk to me about end of life in the same way they’d want to be talked to; they need to put themselves in the person’s position.”

During a conversation

- Be confident and straightforward, and don't hide behind medical terminology. It's much harder speaking to someone when they're obviously really uncomfortable.
- Be honest but empathetic. They need to know what they are dealing with and what each change in their condition will bring but please consider that it can still be hard to hear.
- Listen to them. Their wishes and perception of quality of life may differ to yours.
- Look at them as a whole person, not as someone with just physical needs; they have emotional needs too. It is not easy for a young person to come to terms with knowing that they won't live a long, full life. They may miss out on things like having their own family or a fulfilling career, seeing friends or family marry and seeing siblings, nephews and nieces grow up.

"I Was relieved that they said it, to be honest. I finally knew what was going on."

"I AM DEEPLY DISAPPOINTED IN THE EMOTIONAL SUPPORT GIVEN. THE CARE HOME DOES NOT BELIEVE IT IS THEIR RESPONSIBILITY TO CHECK HIS EMOTIONAL STATE. THEY SEE THIS AS THE RESPONSIBILITY OF SOCIAL CARE. SOCIAL CARE VISITS HIM ONCE A YEAR WITH NO FOLLOW UP."

"There is lots of reflection but also lots of anger, frustration and sadness."

"EVERYONE IS BUILDING - CHILDREN AND CAREER, I'M SHRINKING. HOW MUCH HAVE I ACHIEVED?"

"Use simple language, we don't hear what is being said if it is wrapped up in medical terminology."



“End of life can be a long process and there is a need to ‘check in’ on how he or any other young person is doing whilst they still enjoy the day to day.”

After a conversation

- Answer their questions; follow up on anything they have asked for or of you.
- Give them the option of talking to someone else. They may need additional information or support e.g. spiritually or emotionally.
- Provide the opportunity to talk later if they want to. There is often a lot to take in and they may need time to reflect and make decisions or even change their mind.

"THIS LATEST NEWS HAS CATAPULTED ME INTO A THOUGHTFUL PHASE - A KIND OF "TAKING STOCK". IT FEELS REALLY WEIRD."

“If there is something bad round the corner I can take that information and embed it into my care plan and into life.”

Think about their families

Families are important; everything that happens to the young person affects them too. Close friends can also mean a lot. Both can be part of the care team, they can help you to get to know the young person and understand them better.

It can help their families greatly afterwards to know they have done everything they can. At times, it can be hard for young people to talk to their families though, because it can be really upsetting. So it's really helpful to have someone outside the family to talk to if they need it.

"TWO YEARS LATER WE STILL GET COMFORT KNOWING WE DID IT FOR HIM, WE GAVE HIM THE BEST END OF LIFE, AS HE WANTED IT TO BE."

"We had a long hard battle to get to where we were in the end."

"Mel wanted a memorial bench... we were able to do that and were not left thinking are we doing this right."

"Sometimes it helps to speak to someone outside the family, especially if it's emotional."

Then work out what you can do to help them have the best quality of life possible and live their short lives to the full!

Other things that might be important to them:

- Are they in the right care environment?
- Have they got all the equipment they might need?
- Are they about to transition to adult care and if so is everything in place? It is important to parallel plan for ongoing care and support in adult services as well as for end of life care.
- Contact with their peers; are there any peer support groups (either in person or through social media) you know of which may be helpful for them to contact?

Where next?

We hope this guide has given you insights into and ideas on how to have end of life conversations with young adults. Open, sensitive conversations can lead to a better quality of life. With the messages from young adults we hope that you feel more confident to broach these conversations.

There may be times when end of life conversations are not desired but it is important to at least provide the opportunity for them to take place. Let the young person know that you are there for them if and when they feel ready.

A conversation now can give peace of mind to both them and their families, allowing young adults to live their short lives to the fullest.

Useful Resources

Dying Matters has a wide range of information and resources to support people to talk more openly about dying, death and bereavement. www.dyingmatters.org

The National Council for Palliative Care has produced a range of helpful publications about end of life care and planning. These are available on www.ncpc.org.uk/publications

Together for Short Lives produce a range of resources to support palliative care for children and young people, including a series about end of life planning and a Transition Guide. www.togetherforshortlives.org.uk

The Together for Short Lives Transition Taskforce is a UK-wide project to enable young people with life-limiting conditions to achieve their aspirations in adult services. www.togetherforshortlives.org.uk/transitiontaskforce

The STEPP project

A research project undertaken by Professor Bryony Beresford from the Social Policy Research Unit at the University of York on behalf of Together for Short Lives, the National Council for Palliative Care and Hospice UK. The project looked at examples of positive practice in transition to adult health settings for young people with life-limiting conditions. www.togetherforshortlives.org.uk/STEPPproject

Bridging the Gap

A research project undertaken by Professor Jane Noyes at Bangor University about the palliative care elements of a successful transition to adult services.

Report: www.togetherforshortlives.org.uk/BridgingTheGapProject

Guide: www.togetherforshortlives.org.uk/BridgingTheGapGuide

Muscular Dystrophy Campaign has produced various publications which are available at www.muscular-dystrophy.org

- Becoming a man – Life with Duchenne muscular dystrophy (2010)
- Becoming an adult – Transition for young men with Duchenne muscular dystrophy (2010)
- Guide to transition for 13-25year olds with muscular dystrophy (2010)

Cllic Sargent provides information and support for young adults with cancer. www.cllicsargent.org.uk

Cystic Fibrosis Trust provides information and support to people with cystic fibrosis and their families. www.cysticfibrosis.org.uk

Department of Health: End of Life Care Strategy (2008) available at www.orderline.dh.gov.uk and quote: 284109/End of Life Care Strategy

Creating Responsive Environments for People with Profound and Multiple Learning Difficulties (2nd ed) London: David Fulton. Author Dr Jean Ware (2003)

Identifying and Addressing the Needs of Adolescents and Young Adults with Cancer www.ncbi.nlm.nih.gov/books/NBK179879/

Breaking bad news: supporting parents when they are told of their child's diagnosis. www.rcn.org.uk

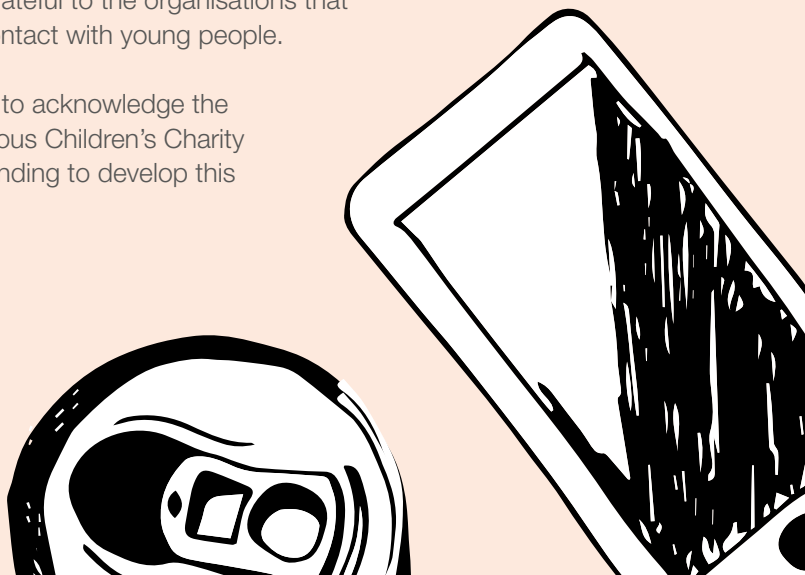
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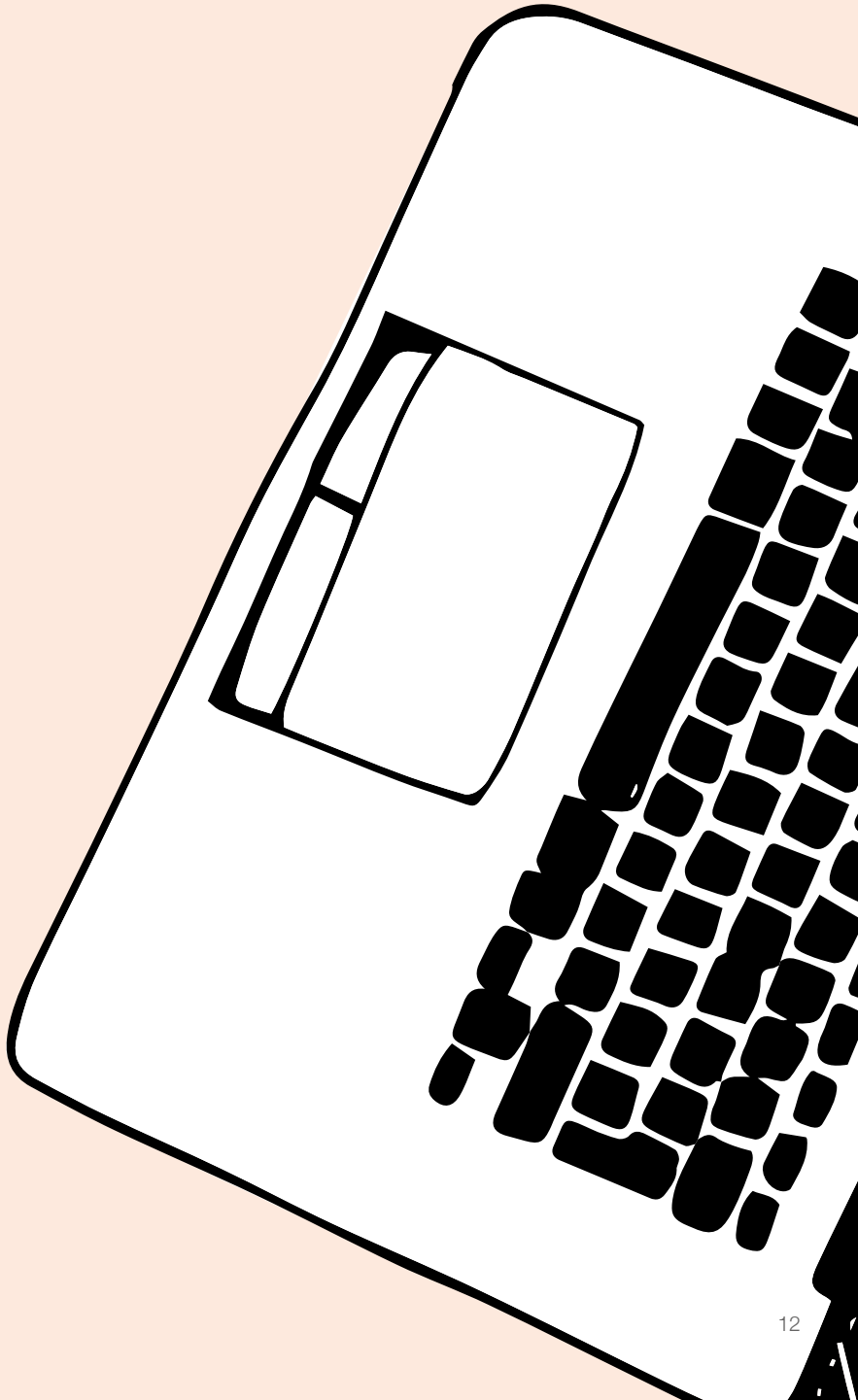
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About us

Together for Short Lives is the leading UK charity that speaks for all babies, children and young people with life-threatening and life-limiting conditions and those who support, love and care for them. Together for Short Lives leads a UK wide Transition Taskforce which aims to improve the experiences of young people with life-limiting conditions as they move into adulthood.

For further information, please contact

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Together for Short Lives is a registered charity in England and Wales (1144022) and Scotland (SC044139) and is incorporated as a company limited by guarantee (7783702).

The National Council for Palliative Care (NCPC) is the umbrella charity for all those involved in palliative, end of life and hospice care in England, Wales and Northern Ireland. We believe that everyone approaching the end of life has the right to the highest quality care and support, wherever they live and whatever their condition. We work with government, health and social care staff and people with personal experience to improve end of life care for all. NCPC leads the Dying Matters Coalition which aims to change public attitudes and behaviour around dying, death and bereavement.

For further information, please contact

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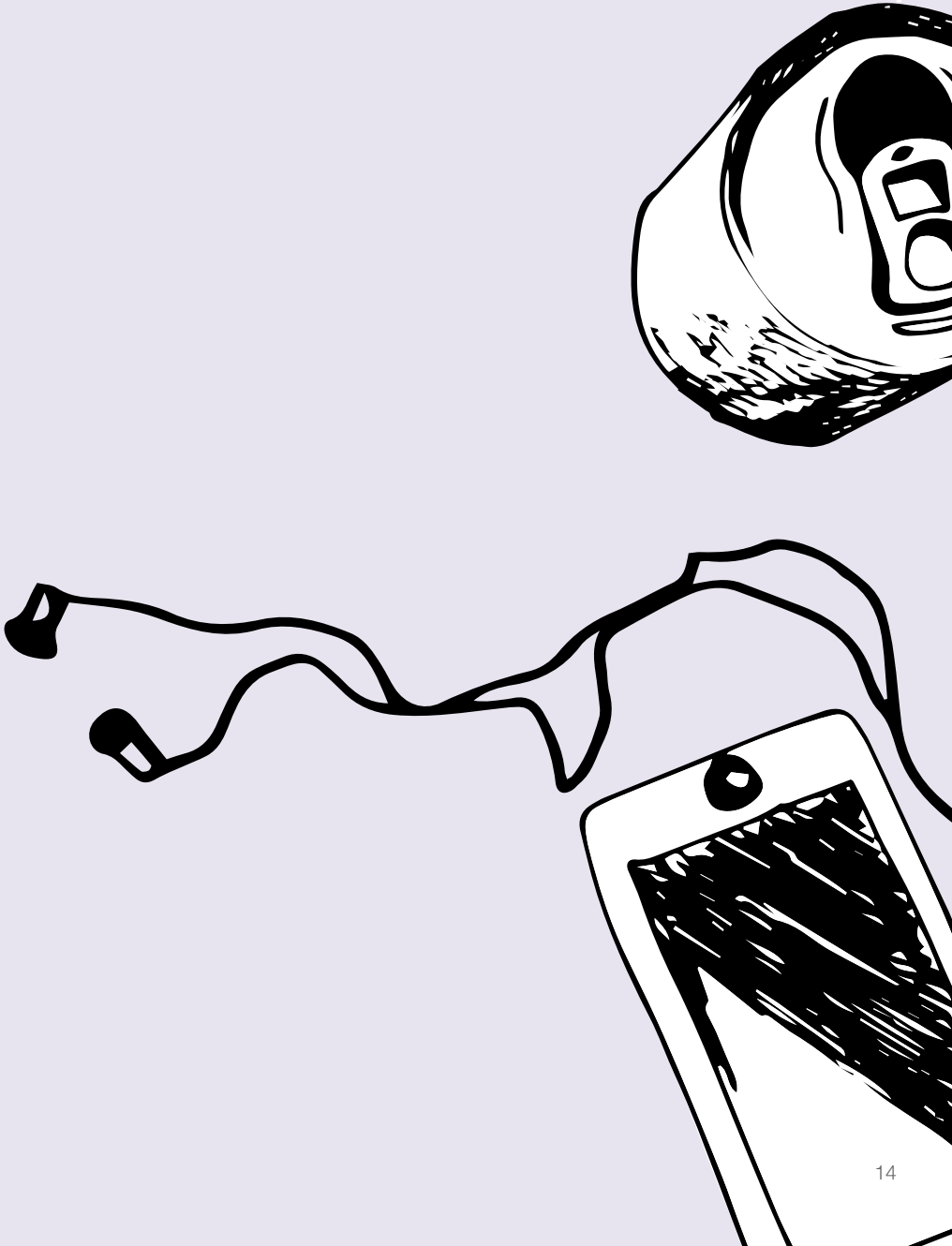
www.dyingmatters.org

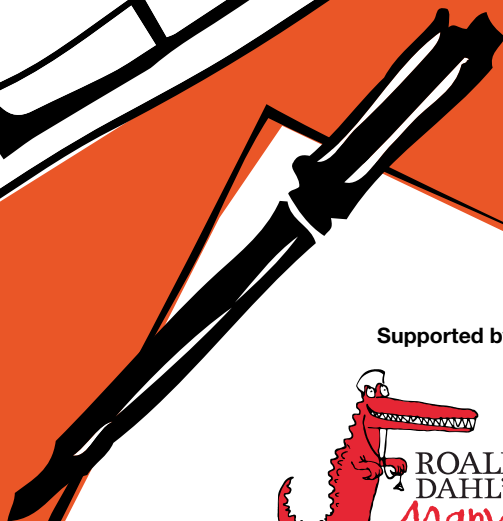
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