

Make it a JOY

Working with parents of children
with serious illness and bereaved parents



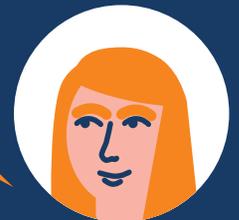
As professionals, we have recognised we have a very important role to play when working with bereaved parents to change support and services for the better.

But how do we work with families compassionately and collaboratively when talking about their children and their care?

Researchers from Kings College London and the Universities of York and Leeds worked with 13 parents to answer this question.



"The opportunity to talk about my child is a good day".



1. COMMUNICATION IS KEY



DO LISTEN.

Parents want us to listen - really listen - to their experiences.



DON'T BE INCONSISTENT OR UNRELIABLE.

Call when you say you will, feedback when you promised and set clear boundaries.



DO COMMUNICATE REGULARLY and CLEARLY.

Parents want to know how they are making a difference by sharing their story. So, set clear expectations for the project and regularly share progress and outcomes.



DO BE MINDFUL

of potential triggers.



DON'T JUST TICK A BOX.

Meaningfully engage parents in discussion - make them feel valued. Be aware of unequal power dynamics. There is a risk of tokenism and losing the parent perspective.



DON'T MAKE ASSUMPTIONS - JUST ASK.

Don't assume families won't want to take part, for example, they are too busy, or it's too soon after the child's death.

2. BUILD RELATIONSHIPS

“Make it a joy to work together”

DO SET BOUNDARIES.

Be clear about how you'll work together, why you are asking them for certain information and act on their feedback.

DO TAKE THE TIME TO BUILD RAPPORT.

Parents want us to take the time to understand their story; and be active co-creators of the project.

DON'T DISREGARD THE PARENT VOICE.

Don't consult with families and then do what you think is right anyway!

DO CARE.

Offer parents the support that they need.

DON'T SHARE ANYTHING WITHOUT CONSENT.

Parents must consent to their words and experiences being shared. Even if it is anonymised.

DON'T USE INSENSITIVE LANGUAGE.

Check the terminology that parents want you to use. For example, is 'terminally ill child' appropriate?



3. BE INCLUSIVE

“Not every family needs the same thing”



DO

DO ENGAGE WITH A DIVERSE GROUP OF PARENTS.

Personalise activities, communication styles and ways to engage to meet parents' needs - whether that be mums, dads, and families of different backgrounds.

DO RESPECT PARENTS' CHOICES.

Choices families make are different - we need to be respectful that not all parents want the same thing. Parents may wish to contribute differently depending on the day.

DO MAKE ENGAGEMENT FLEXIBLE.

Consider online, in person or home visits to support and work with parents.

DON'T

DON'T ASSUME EVERYONE CAN USE TECHNOLOGY.

Be mindful of digital exclusion, and work with families to find the best way to communicate.

DON'T USE JARGON.

Agree together with parents what key terminology will be used in your interactions.



Let's work together to improve care for children.

SCAN to find out more...

