Introducing the Child Death Review Toolkit

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CDR
Supporting
compassionate
child reviews

Outline

Why involve parents in CDR?

How we developed the toolkit

Research project: Involving parents and staff in learning from child deaths

Toolkit demonstration

Child Death Review Meeting

Background

2018 Child Death Review (CDR) statutory guidance

Parents have questions even if diagnosis established before their child’s death

Parents have unique insights into their child’s illness and treatment

Families’ concerns are often not heard

Improving parental involvement in CDR should lead to greater learning from deaths and better parental support

Aim

To understand existing CDR practice by exploring views of parents and healthcare professionals

To co-design a best-practice toolkit to support parental involvement in CDR following expected deaths of children

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Interviews with parents & professionals

Parents recruited across England, following expected child deaths

in hospital, hospice or at home with palliative care.

Interviews focussed on experiences of CDR, held between January and June 2023.

24 parents interviewed

5 sites for professional interviews: 3 PICU, 2 palliative care

21 professionals

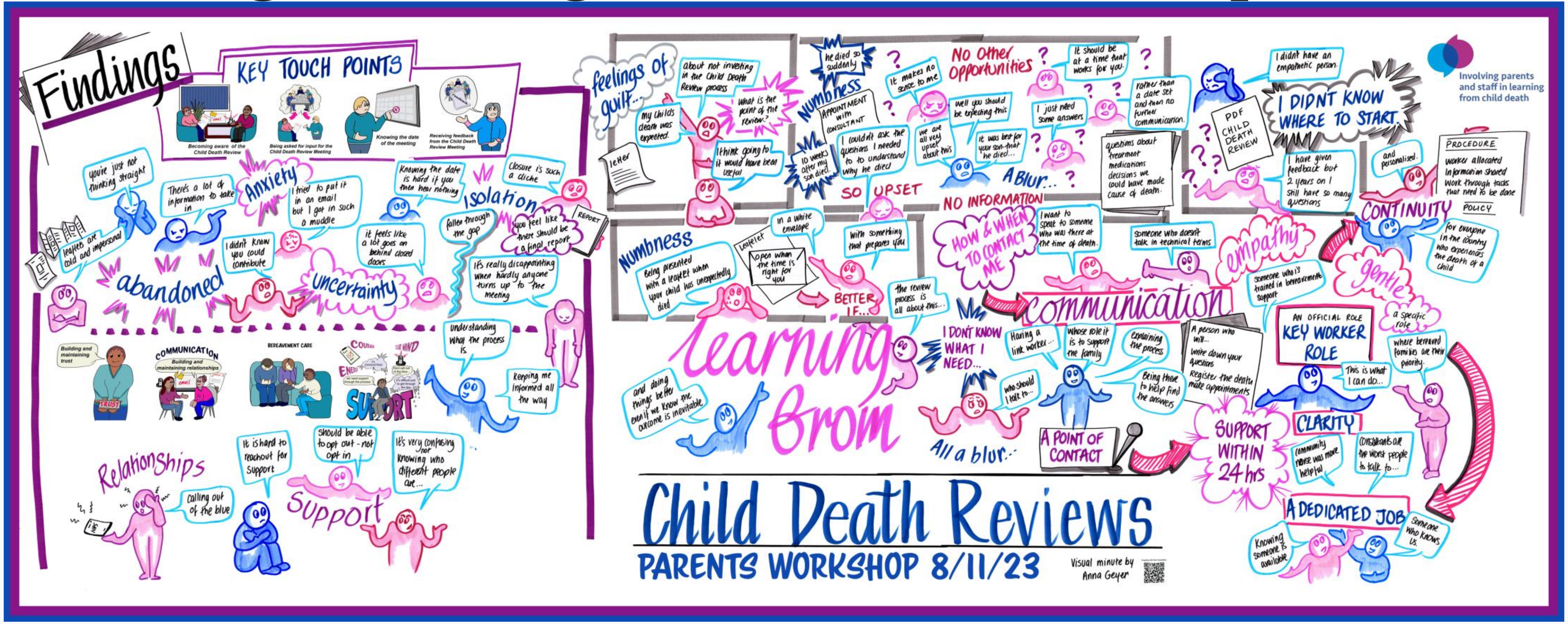
Interviews focussed on experiences of involving parents in CDR, and the barriers and enablers to this.

Data analysis

Interview transcripts studied to identify ‘emotional touchpoints’ relating to CDR

> ‘the key moments and places … where people come into contact with the services and where their subjective experience is shaped, and therefore where the desired emotional and sensory connection needs to be established’

Co-design meetings – Parents workshop



Reviewed findings from parents' interviews

Agreed touchpoints & priority areas for improvement

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Co-design meeting – Professionals’ workshop

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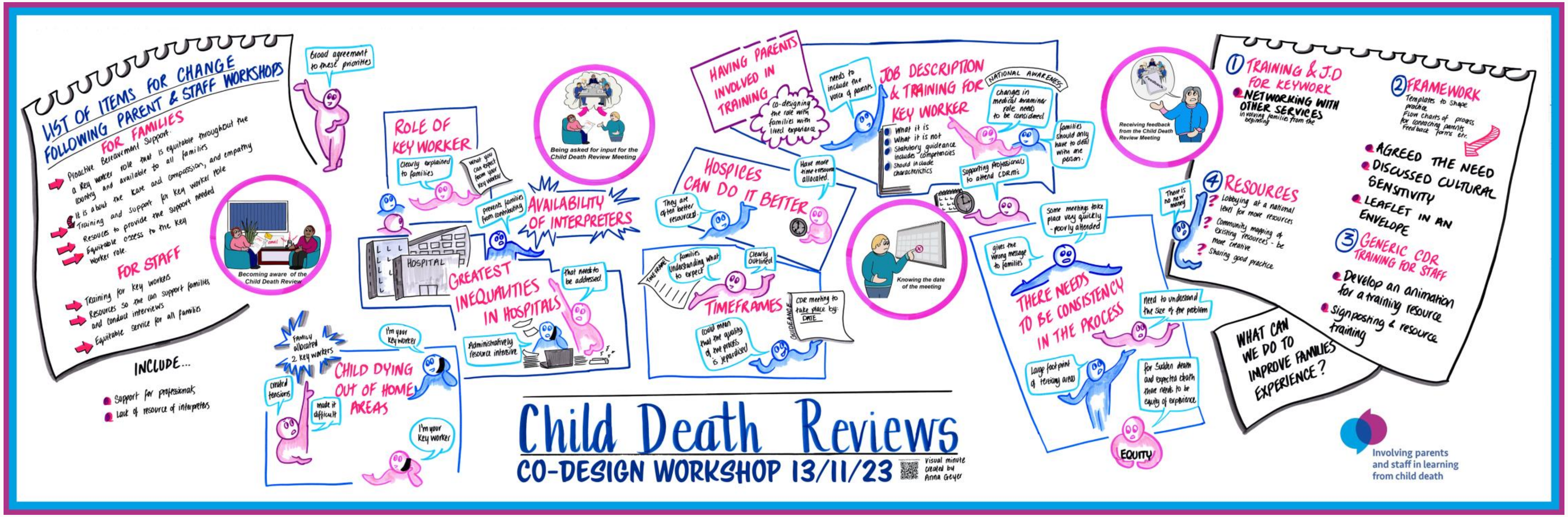
Discussed key findings

Identified priority areas for improvement

Co-design meeting – parents, professionals and stakeholders



Presented parents' touchpoints

Agreed priorities for improvement

Considered different tools to help solve issues

Formed working groups to develop tools

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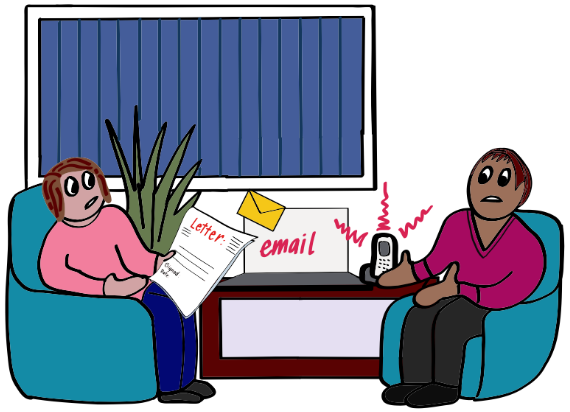
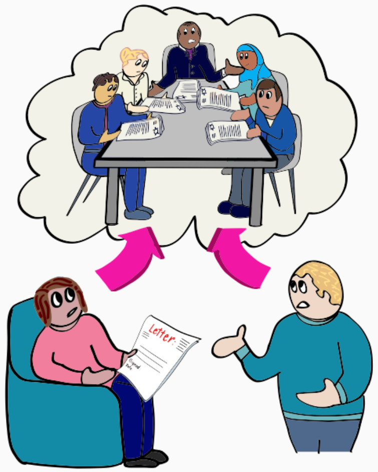
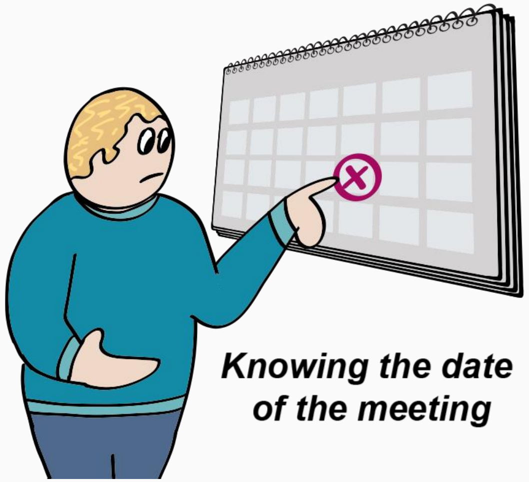
Touchpoints



Becoming aware of the Child Death Review



Being asked for input for the Child Death Review Meeting



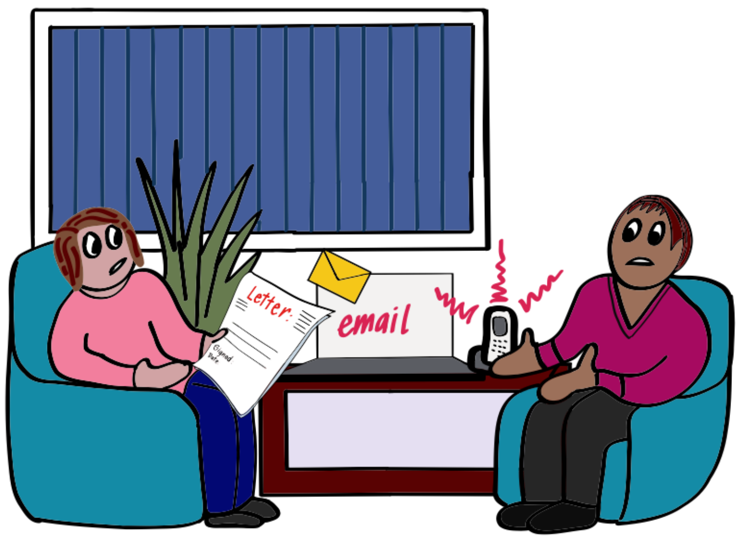
Knowing the date of the meeting

Receiving feedback from the Child Death Review Meeting

Supporting principles

Becoming aware of the CDR meeting

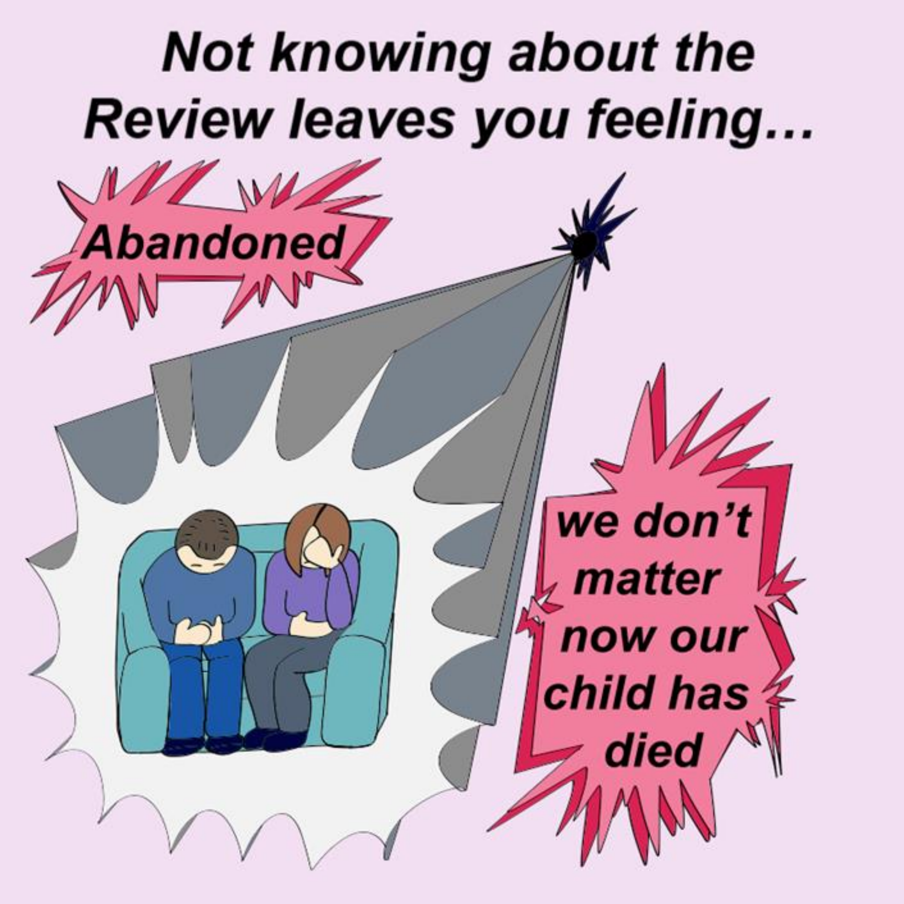
It was very important how CDR was explained to parents, some only read about it in leaflets, others had telephone calls from professionals that they had never spoken with before.



Becoming aware of the Child Death Review

“And then we got this random call from this random person, who said, “I'm from child bereavement.” We went, “Sure. Okay. Right. Fine.” “Oh, and I'm going to be representing you at this review.”” Parent 16

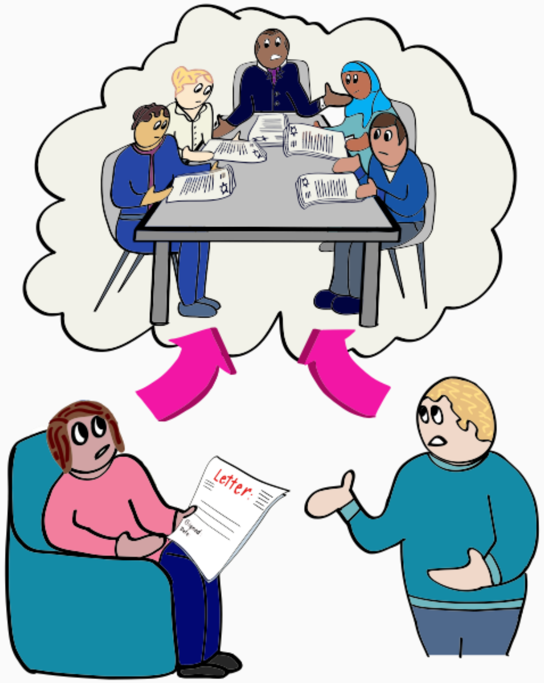
“I think there’s something very cold and impersonal about having a leaflet. Having those sort of honest conversations with a real human being, I think they give you a lot more comfort and they give you a lot more involvement.” Parent 12



Being asked for input

Parents all found it very difficult to provide feedback or ask questions for the CDRM as there was no format or structure to do so. Many were discouraged by the lack of guidance.

Parents also found it difficult to ask questions in a non-judgmental manner when they had previously had good relationships with their child’s care team, often for many months or years.



Being asked for input for the Child Death Review Meeting

"And she said, oh can you put it in an email. I was just like oh my God you know how long it's taken me to actually pluck up the courage to call you and now you're saying you want me to put it in an email, okay. So then I tried to write an email and…I got myself all muddled,… I rewrote it about twelve times." Parent 08

"I was happy to be able to ask some questions. I found it quite difficult because I didn't want to be blaming anyone, I just had questions. So I found that balance quite difficult…" Parent 06

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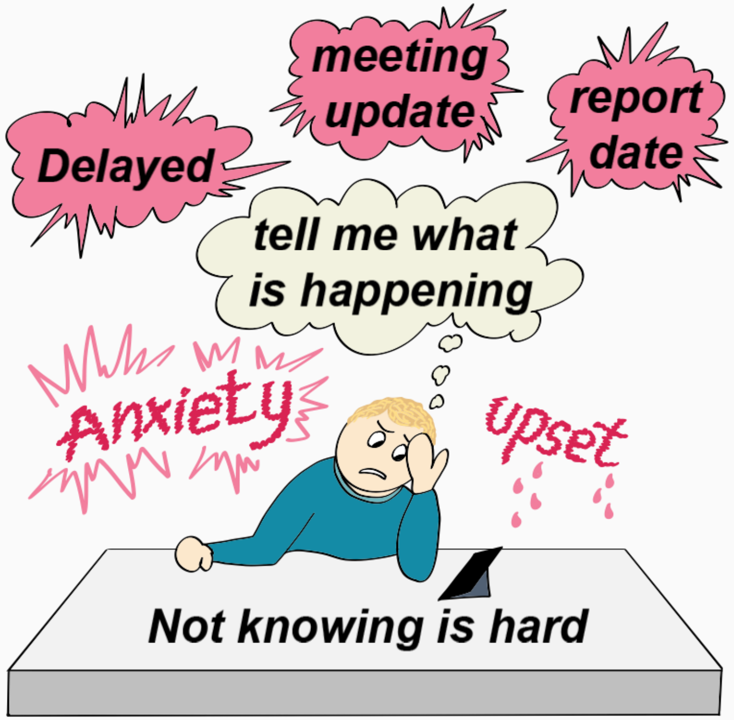
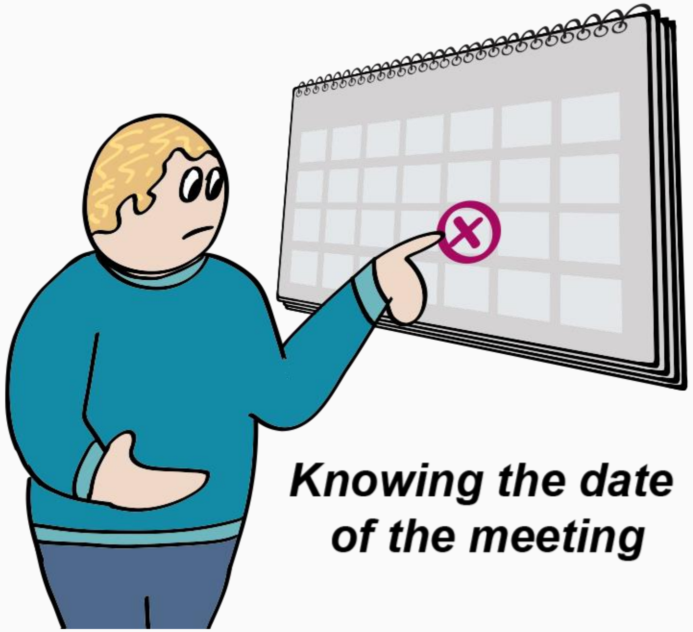
Parents did not necessarily know the date on which the CDRM was to be held, but this date often caused further anxiety in the lead-up to it, and distress if the meeting needed to be postponed; this was compounded by poor communication.





“I was thinking, ‘Hang on a minute. This has been eight months. We should have heard by now.’ I was really horrified when [they] said, ‘Yeah, it’s happening on 7th September.’ I said, ‘No one told me.’ We’ve fallen through the gap…” Parent 23

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Receiving Feedback

Few parents received feedback after the CDR meeting, but most wanted feedback.

“Much the same as you get reports all the way through every appointment your child has, when they're alive, and so, actually, you kind of feel like, well, maybe there should be a final one.” Parent 14

“They never gave us any feedback on it or anything. I think it would’ve been nice... Because there was some feedback that we gave that could detrimentally impact another family…” Parent 19

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Communication and building relationships

"I just I didn't want it to be like, oh right tick, we've sent that, that's gone out to that family that's okay, you know, tick, oh you contacted them tick like we've now told them about that. But actually I think it's that relationship isn't it…" Parent 08

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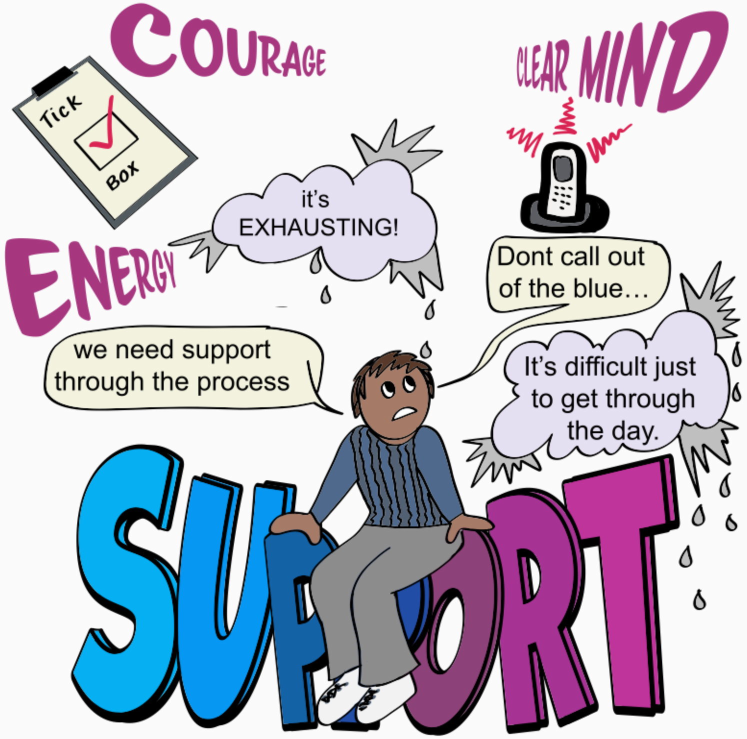
Bereavement care and support

"when a baby's born, you have midwives and health visitors. It's the happiest time of your life and you have scheduled day[s]... Why you don't have the same bereavement care when your world's falling apart…that would be so beneficial for families when they're in survival mode. They're in absolute shock, devastation."
Parent 18



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Priorities for action

Parents

All families to have access to keyworkers

Training for keyworkers

Resources for keyworkers

Proactive bereavement support for families

Professionals

Equitable service for all bereaved families

Training for keyworkers

Adequate resources to conduct reviews and support families

What's in the toolkit…

Parents:

A flow chart detailing suggested contacts with bereaved families

Template letters to support communication with families

A contact tracker

A feedback form

An easy read leaflet

Professionals:

An animated infographic

Videos for keyworkers about CDR

A keyworker role description

All resources freely available on NCMD website

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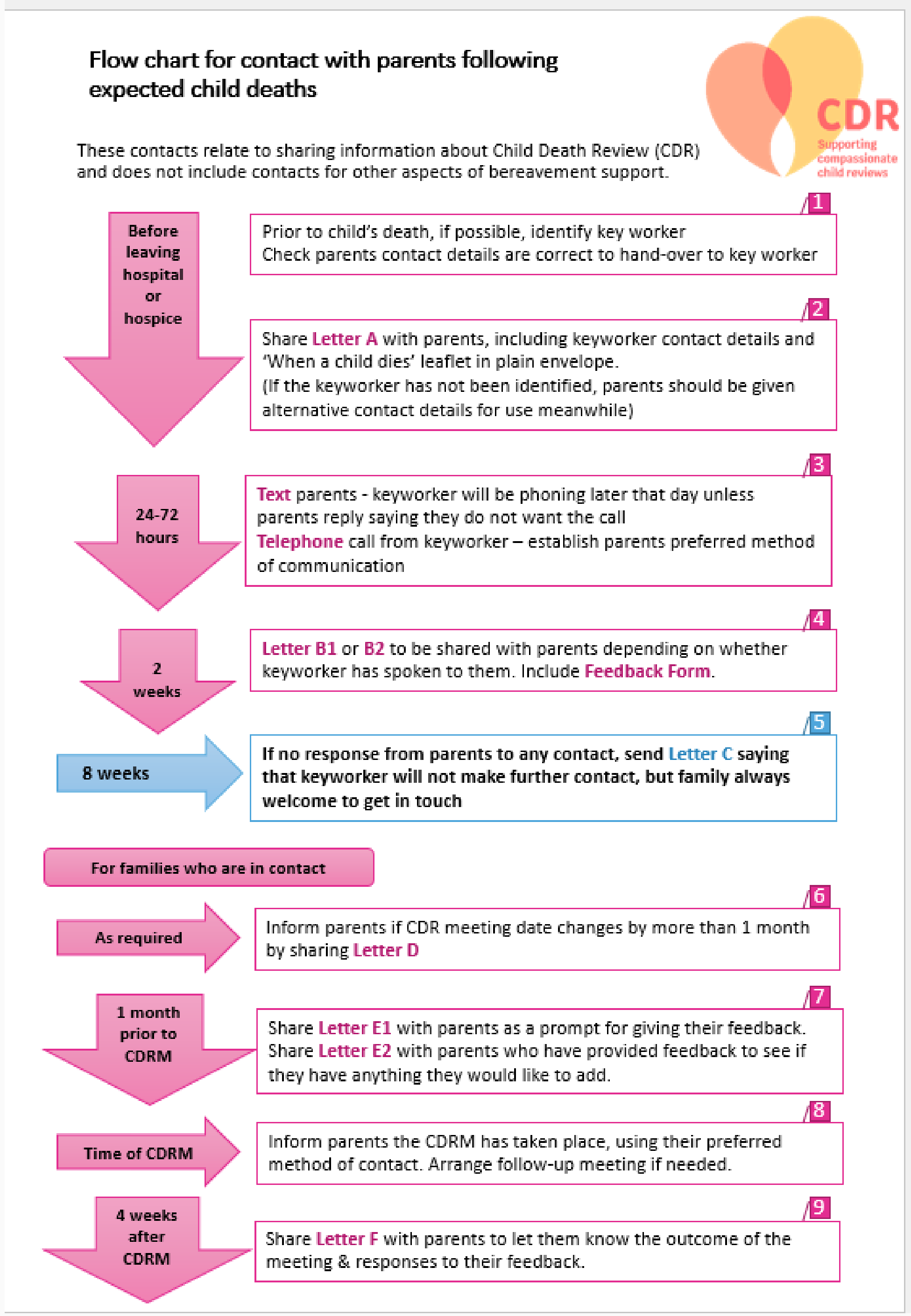
Flow chart and guidance notes



Flow chart for contact with parents following expected child deaths

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These contacts relate to sharing information about Child Death Review (CDR) and does not include contacts for other aspects of bereavement support.

Before leaving hospital or hospice

1 Prior to child's death, if possible, identify key worker
Check parents contact details are correct to hand-over to key worker

2 Share **Letter A** with parents, including keyworker contact details and 'When a child dies' leaflet in plain envelope.
(If the keyworker has not been identified, parents should be given alternative contact details for use meanwhile)

24-72 hours

3 **Text** parents - keyworker will be phoning later that day unless parents reply saying they do not want the call
Telephone call from keyworker – establish parents preferred method of communication

2 weeks

4 **Letter B1** or **B2** to be shared with parents depending on whether keyworker has spoken to them. Include **Feedback Form**.

8 weeks

5 **If no response from parents to any contact, send Letter C saying that keyworker will not make further contact, but family always welcome to get in touch**

For families who are in contact

As required

6 Inform parents if CDR meeting date changes by more than 1 month by sharing **Letter D**

1 month prior to CDRM

7 Share **Letter E1** with parents as a prompt for giving their feedback.
Share **Letter E2** with parents who have provided feedback to see if they have anything they would like to add.

Time of CDRM

8 Inform parents the CDRM has taken place, using their preferred method of contact. Arrange follow-up meeting if needed.

4 weeks after CDRM

9 Share **Letter F** with parents to let them know the outcome of the meeting & responses to their feedback.

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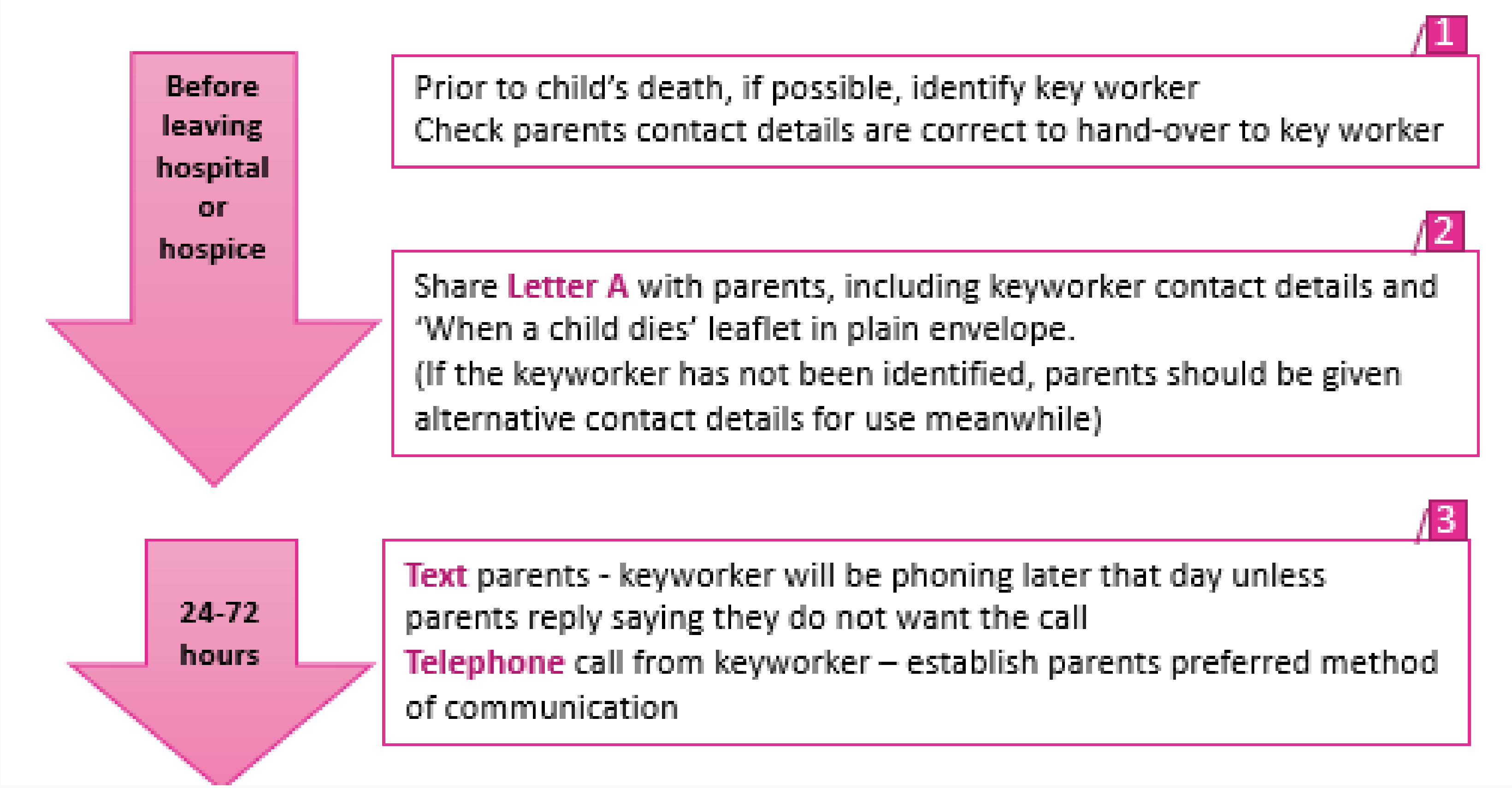
Letter A – Before leaving hospital or hospice



Before leaving hospital or hospice

1

Prior to child's death, if possible, identify key worker
Check parents contact details are correct to hand-over to key worker

2

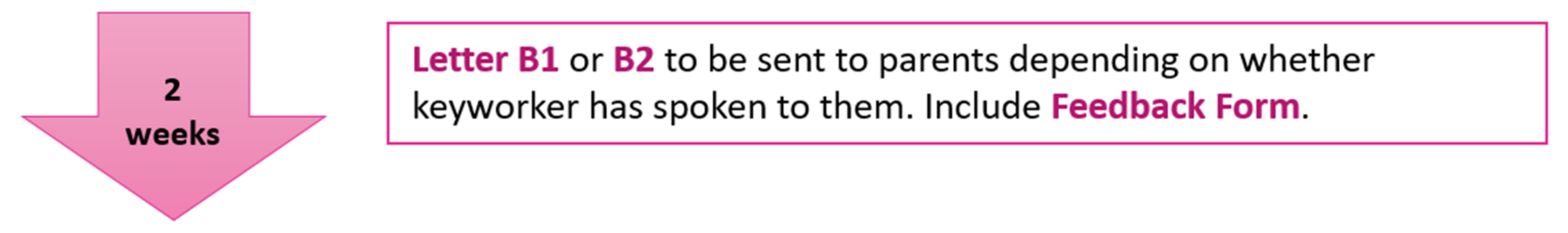
Share **Letter A** with parents, including keyworker contact details and 'When a child dies' leaflet in plain envelope.
(If the keyworker has not been identified, parents should be given alternative contact details for use meanwhile)

24-72 hours

3

Text parents - keyworker will be phoning later that day unless parents reply saying they do not want the call
Telephone call from keyworker – establish parents preferred method of communication

Letter B1, B2 and C



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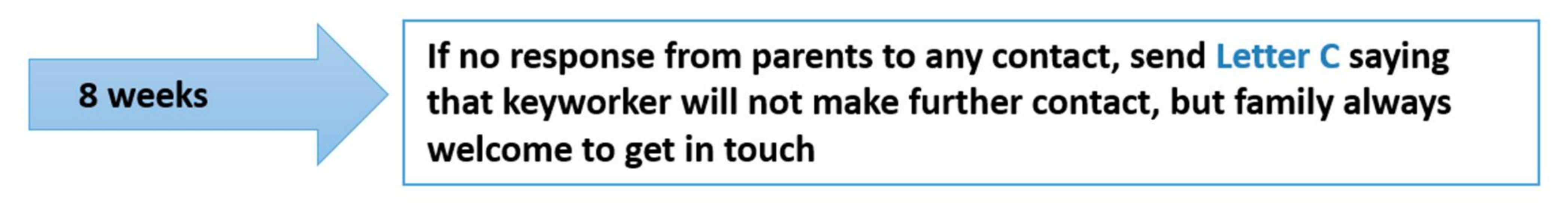

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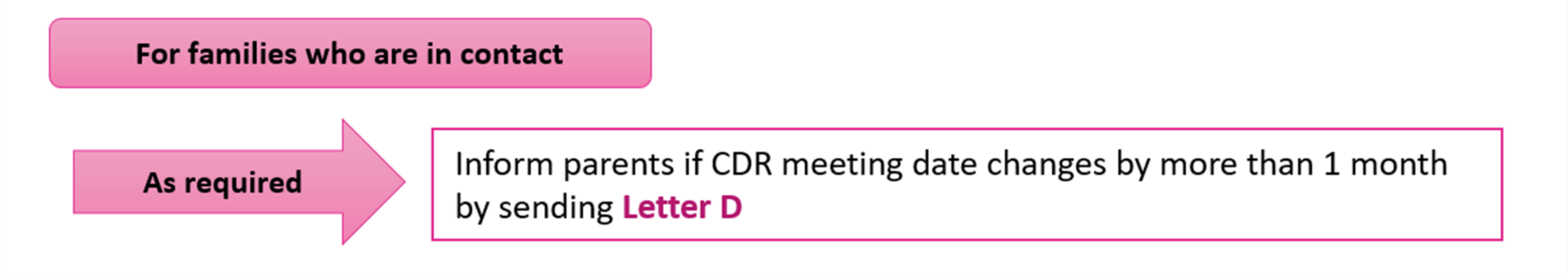
Letter D, E1 and E2



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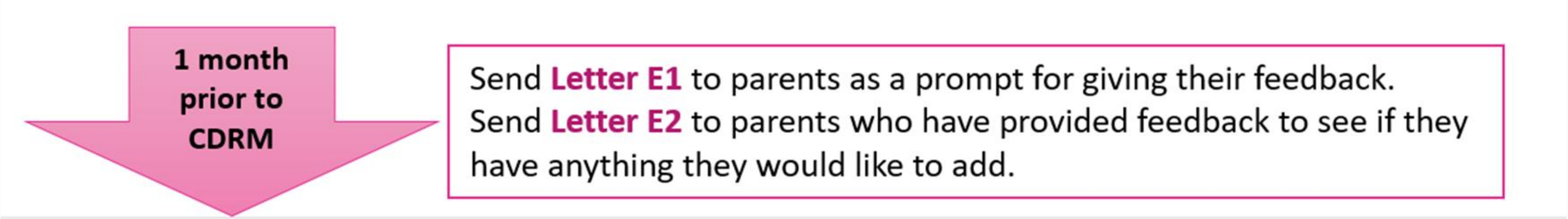

1 month prior to CDRM

Send **Letter E1** to parents as a prompt for giving their feedback.
Send **Letter E2** to parents who have provided feedback to see if they have anything they would like to add.

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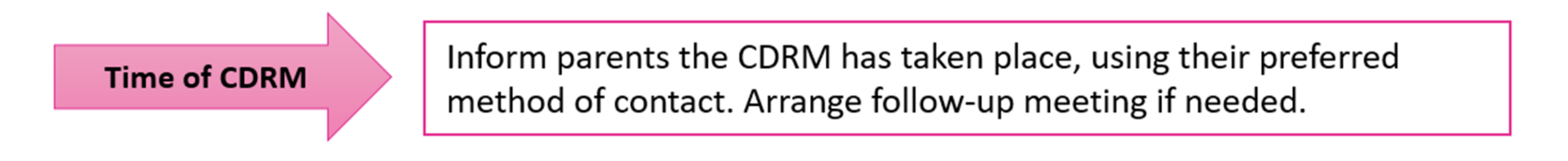
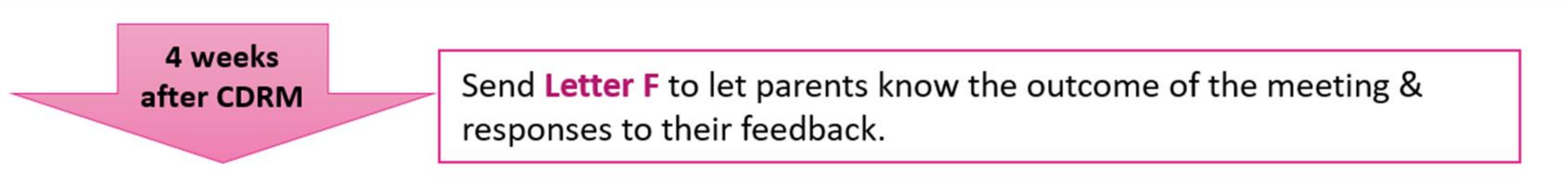
Shortly after the CDRM, and letter F



Time of CDRM

Inform parents the CDRM has taken place, using their preferred method of contact. Arrange follow-up meeting if needed.



4 weeks after CDRM

Send **Letter F** to let parents know the outcome of the meeting & responses to their feedback.

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Feedback form

Is there anything about your child’s care that you still have questions about?

Is there anything you found particularly difficult or challenging about getting the care or treatment your child needed?

How well did healthcare professionals communicate with you throughout your child’s care?

Do you have any questions about the care your child received towards the end of their life and when they died?

Is there anything you would like us to know about what you felt went well during your child’s care?

Is there anything else that you would like to tell us or ask us

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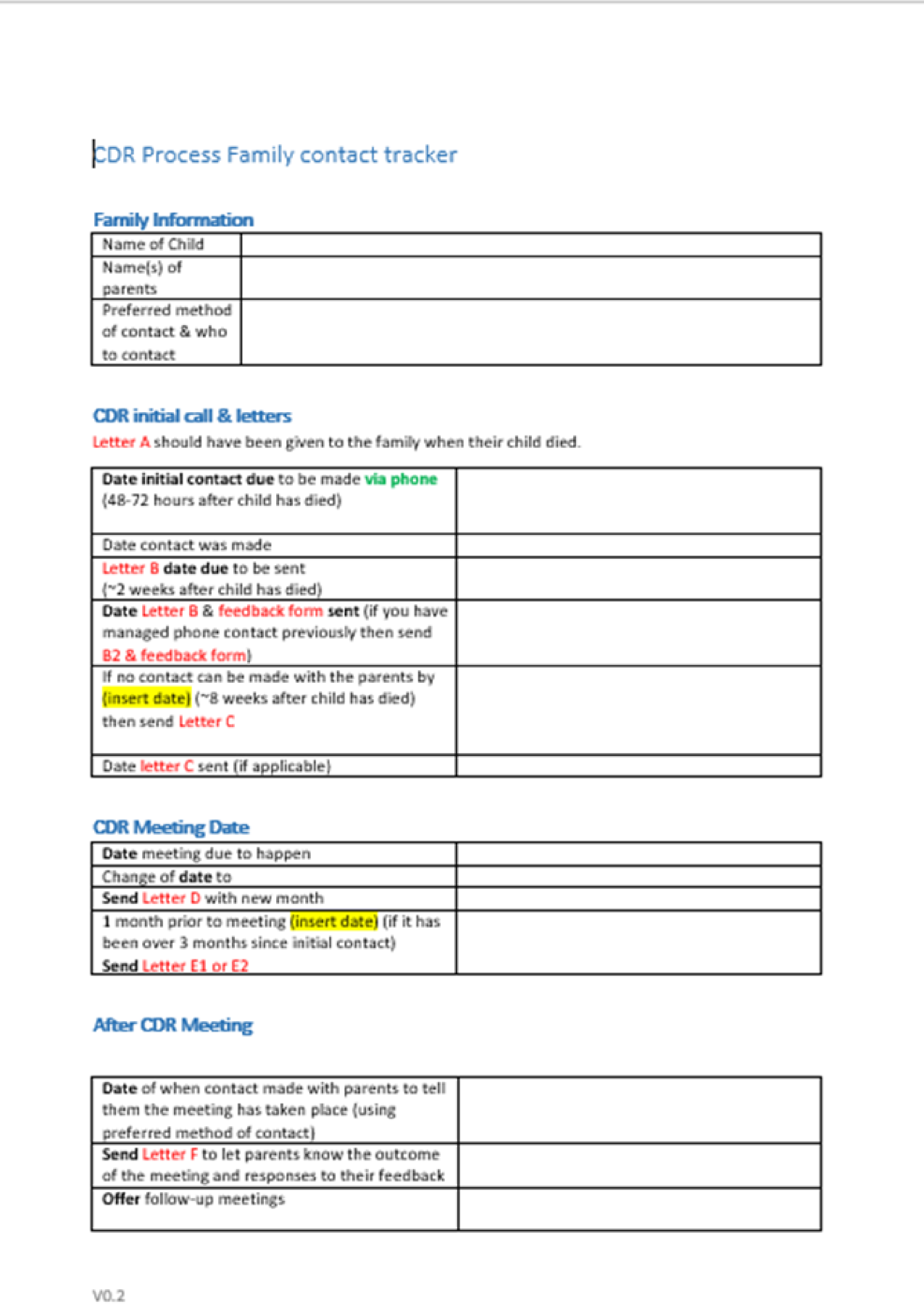
Contact tracker form



CDR Process Family contact tracker

Family Information

Name of Child	
Name(s) of parents	
Preferred method of contact & who to contact	

CDR initial call & letters

Letter A should have been given to the family when their child died.

Date initial contact due to be made **via phone** (48-72 hours after child has died)	
Date contact was made	
Letter B **date due** to be sent (~2 weeks after child has died)	
Date Letter B & feedback form **sent** (if you have managed phone contact previously then send B2 & feedback form)	
If no contact can be made with the parents by (insert date) (~8 weeks after child has died) then send Letter C	
Date letter C sent (if applicable)	

CDR Meeting Date

Date meeting due to happen	
Change of **date** to	
Send Letter D with new month	
1 month prior to meeting (insert date) (if it has been over 3 months since initial contact) **Send** Letter E1 or E2	

After CDR Meeting

Date of when contact made with parents to tell them the meeting has taken place (using preferred method of contact)	
Send Letter F to let parents know the outcome of the meeting and responses to their feedback	
Offer follow-up meetings	

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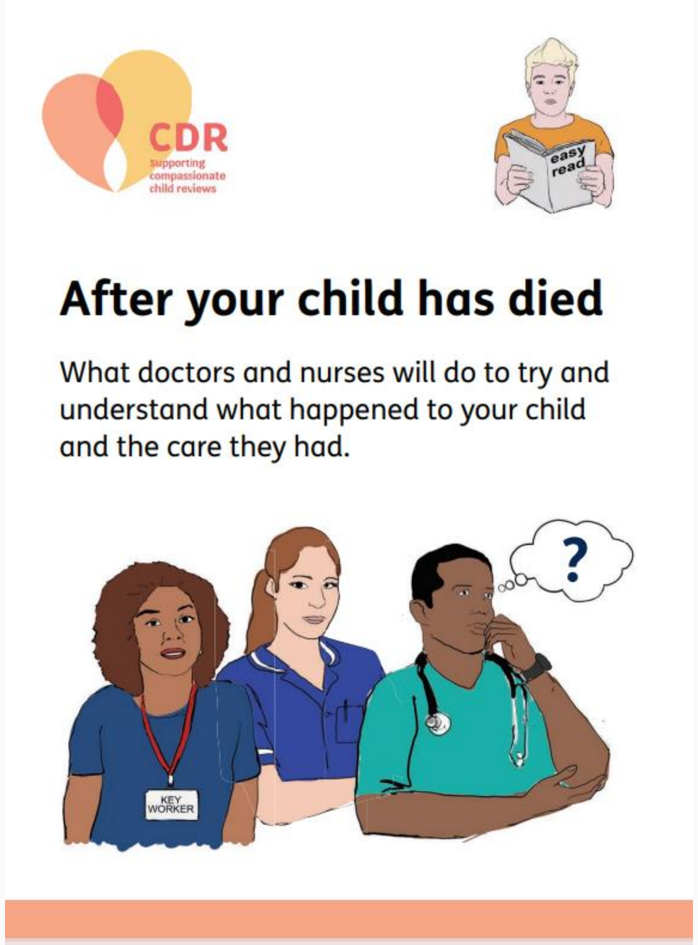
Easy read leaflet



CDR
supporting compassionate child reviews

easy read

After your child has died

What doctors and nurses will do to try and understand what happened to your child and the care they had.

About this booklet

We are very sorry that your child has died.

We know this is a really hard time for you and your family.

You might have some questions about what has happened.

Doctors will try to find out why your child died.

They will also look at what happened and how they can make care better.

This booklet tells you what will happen and what you can expect.

About a review

When a child dies, the hospital will do a **review.**

A **review** is when doctors and nurses look at why your child died.

The review will try to help you and doctors understand what happened.

They look at the care your child got through their whole life. They check to see if your child got the right care for them.

We have a booklet with more information about the review called **When a child dies**.

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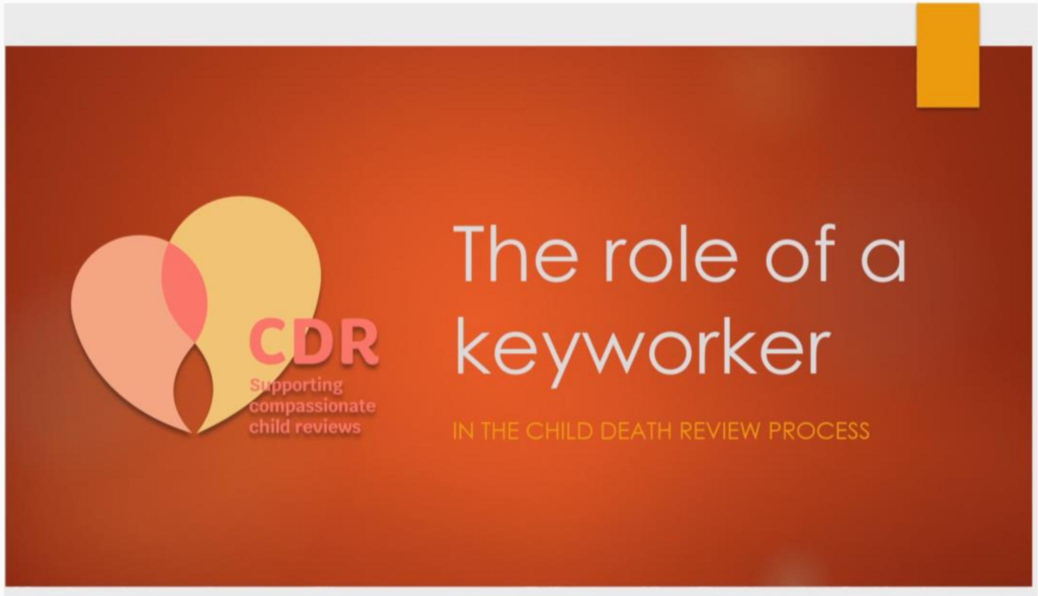
Keyworker tools



CDR
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The role of a keyworker

IN THE CHILD DEATH REVIEW PROCESS

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Keyworker Tools

TO SUPPORT THE INVOLVEMENT OF PARENTS IN THE CHILD DEATH REVIEW PROCESS

Template keyworker role description

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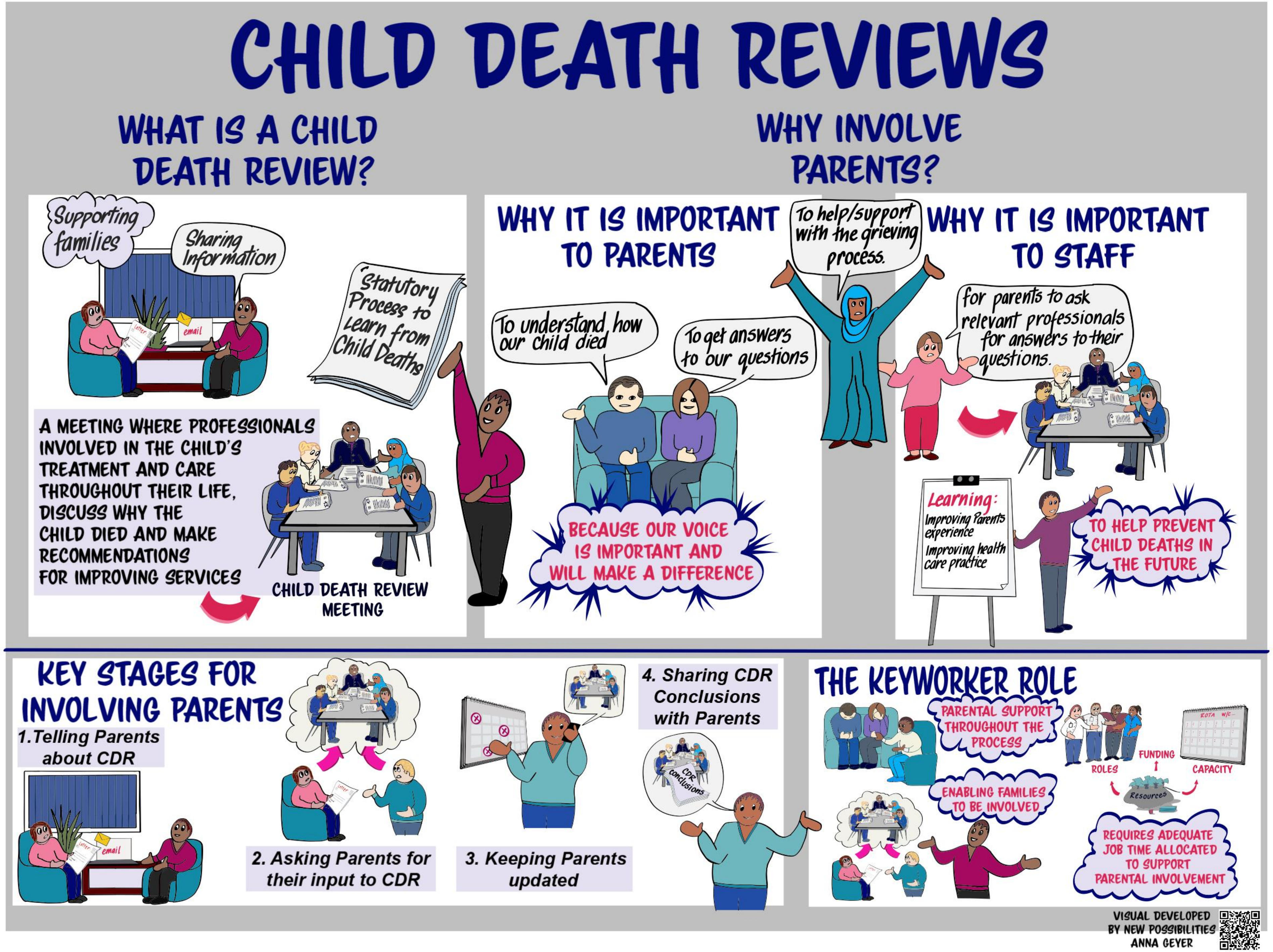


CHILD DEATH REVIEWS

WHAT IS A CHILD DEATH REVIEW?

A MEETING WHERE PROFESSIONALS INVOLVED IN THE CHILD'S TREATMENT AND CARE THROUGHOUT THEIR LIFE, DISCUSS WHY THE CHILD DIED AND MAKE RECOMMENDATIONS FOR IMPROVING SERVICES

WHY INVOLVE PARENTS?

WHY IT IS IMPORTANT TO PARENTS

BECAUSE OUR VOICE IS IMPORTANT AND WILL MAKE A DIFFERENCE

WHY IT IS IMPORTANT TO STAFF

TO HELP PREVENT CHILD DEATHS IN THE FUTURE

KEY STAGES FOR INVOLVING PARENTS

1. Telling Parents about CDR
2. Asking Parents for their input to CDR
3. Keeping Parents updated
4. Sharing CDR Conclusions with Parents

THE KEYWORKER ROLE

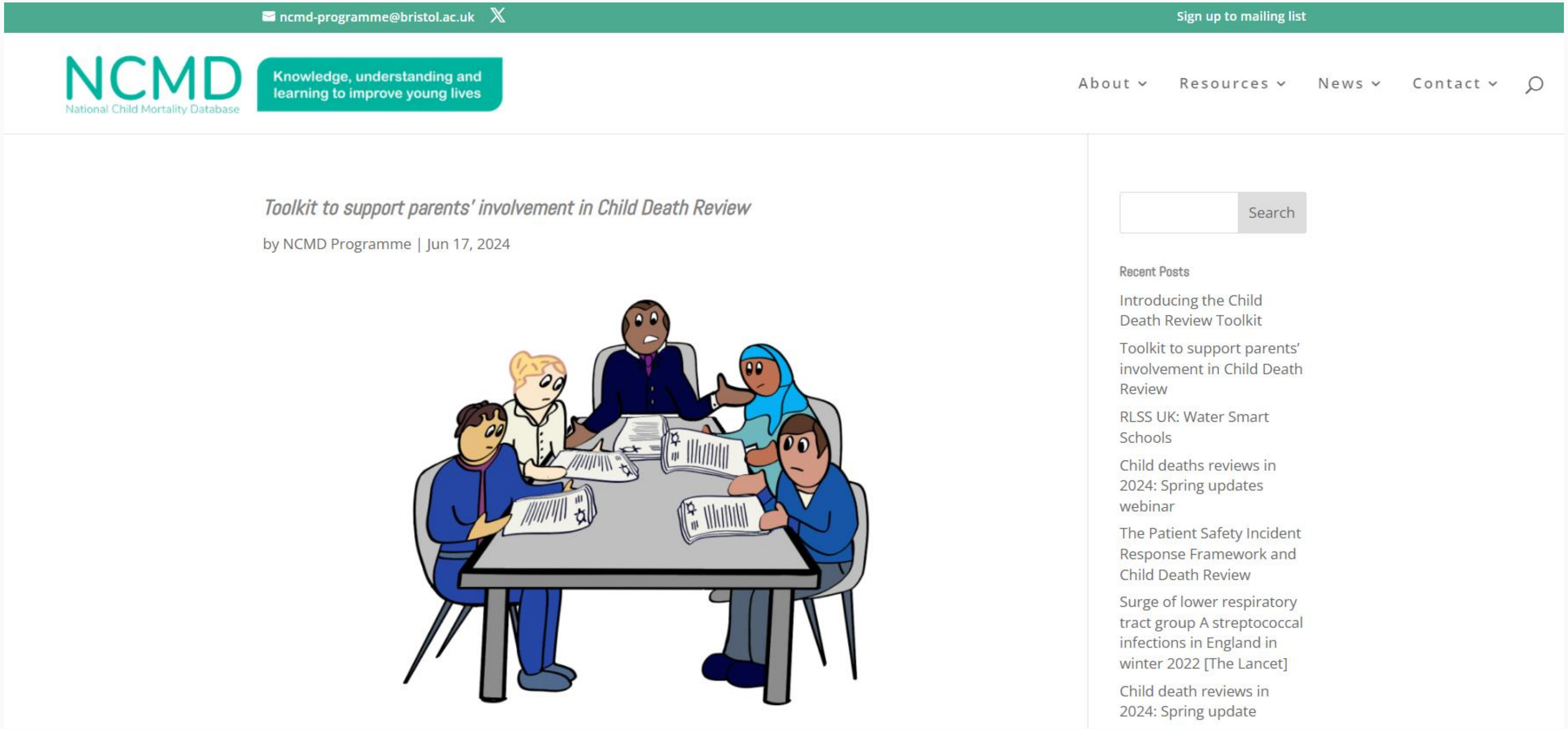
PARENTAL SUPPORT THROUGHOUT THE PROCESS

ENABLING FAMILIES TO BE INVOLVED

REQUIRES ADEQUATE JOB TIME ALLOCATED TO SUPPORT PARENTAL INVOLVEMENT

VISUAL DEVELOPED BY NEW POSSIBILITIES ANNA GEYER

CDR Toolkit website - launch 18 July 2024



Toolkit to support parents' involvement in Child Death Review

by NCMD Programme | Jun 17, 2024

Recent Posts

- Introducing the Child Death Review Toolkit
- Toolkit to support parents' involvement in Child Death Review
- RLSS UK: Water Smart Schools
- Child deaths reviews in 2024: Spring updates webinar
- The Patient Safety Incident Response Framework and Child Death Review
- Surge of lower respiratory tract group A streptococcal infections in England in winter 2022 [The Lancet]
- Child death reviews in 2024: Spring update

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Conclusion


clear information
feedback from review meeting
invited to input to review
review meeting
This is a learning process
Trust
good relationship
told about review


LEADERSHIP
feedback from review meeting
review meeting
invited to input to review
told about review
Child Death Review Meeting

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Thank you to all our team:

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Dr Anna Pease
Jenna Spry
Gayle Routledge

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A Child of Mine
Child Bereavement UK
Edwards Trust
Lullaby Trust
Together for Short Lives
SUDC-UK