



Briefing Paper 7: Involving families in the review process

This guidance was written in conjunction with family carers to help reviewers think about what they can do to meaningfully involve family members at each stage of the process and manage any fears and anxieties that families and reviewers may have.

The Learning Disabilities Mortality Review (LeDeR) programme encourages reviewers to involve families throughout the entire review process or as much as families feel able or want to be involved. National guidance for NHS trusts on how to engage with families and carers whose loved one has died was issued in 2018. This emphasises that families' experiences and insights are a valuable source of learning and that families and carers should be treated as equal partners to identify opportunities for improvement.

There are enormous benefits to involving family members, as they will often have the greatest knowledge of the person who has died and may have thoughts already about how services could be improved based upon their own experiences.

Initial Review stage

If a family member has been identified and contact details provided on the notification form you may want to proceed by:

- Telephoning the family member telling them about the LeDeR mortality review programme, its aims and purpose, and asking them if they would like to be sent further information and possibly become involved in it given the recent death of their relative.
- If yes - make an appointment to meet with them and send them the LeDeR programme information. (These can be found on the LeDeR system dashboard for you to download and save to your PC).
- If no - that is fine, but they may well want to receive the information in the post in case they want to be involved at a later stage or get feedback from you after the review is complete, so do check but be mindful of timescales.

Whether or not they have been identified as someone who knew the person well at the notification stage, we would encourage you to contact a/the family member. You may be told that family members have not been involved with the person for some time, and/or it proves difficult to access names and contact details. In these circumstances it would be good practice to



follow this up - you will want to feel certain it is not possible to notify or include family members in the review before omitting them.

Initial meeting with a family member

Purpose of the initial meeting

- It is important that reviewers are clear about the purpose of the review process, which is to identify learning and sharing of good practice to contribute to the improvement of services for people with learning disabilities.
- It might be helpful to reinforce the point that this is part of a national process of reviews and not an indicator that there are any concerns about the treatment or care of their family member.
- The purpose of the meeting with the family at this stage is to ask them for additional information to inform the timeline and pen portrait and help to make the decision about proceeding to a multi-agency review.

Preparing for the initial meeting

- Set some ground rules about what they can expect from you, what you hope they will feel able to share with you and what will happen to that information. Remind family members that they can rearrange or stop the meeting at any time.
- Discuss the review process: the initial review of one set of case notes and a discussion with someone who knew the person who has died well, and a possible further in-depth multi-agency review. You may want to go through the initial review paperwork and if necessary, leave them a blank copy to look at later.
- Be prepared to explain any terminology such as “potentially avoidable contributory factors.”
- Ask open questions - *“is there anything else that you would like to tell us or you have thought of?”*
- Be empathic and supportive to help people to feel safe and confident that what they share with you is valued and useful.
- Reviewers can anticipate lots of positive experiences being described – staff kindness, supportiveness, close knowledge of the individual, loyalty, real understanding, going the extra mile etc.
- Reviewers may also experience some difficult responses and feelings such as defensiveness, anger or overly passive behaviour - sometimes when we are frightened, distressed, worried and anxious we can come across in these ways.
- Be prepared for these feelings (either those of the family member, another professional or your own).



- If possible go to the meeting with information about local bereavement resources and carers/support groups, to which you can signpost people should they want to make a complaint, need information or support. We have some links to organisations on the LeDeR webpages, but you may know appropriate local sources of support in addition to this.
- Make sure that you have set up some support for yourself after the meeting in case you find it distressing, such as talking it through with a colleague, another reviewer or your Local Area Contact. Ensure these conversations adhere to privacy and confidentiality guidelines.
- Be prepared to answer difficult questions and for all possible outcomes - have an idea of local resources and complaints procedures. If you do not know the answer, be honest and realistic in what you can offer but offer to follow up with information if appropriate. People value honesty and genuine answers.
- Discuss if and how families want feedback from the initial review and whether they want to be involved should the initial review indicate a multi-agency meeting would be needed. This might include them attending the meeting or feeding into the meeting in another way.

Preparing for the multi-agency meeting

Where a multi-agency meeting is indicated you may want to arrange a pre-meeting with the family member to discuss if they would like to attend the meeting, who would be present (their names and roles), and the structure of the meeting, so they know what to expect from the meeting. If you have already met, it may suffice to discuss this by telephone.

If they don't want to attend the meeting in person, they may want to contribute by providing additional information to you on the phone or in writing.

If the family member does want to attend you should:

- Check what support they will need.
- Discuss and agree what needs to happen if they don't understand what is being said, or they get upset or angry at any point.
- Make sure that the others attending the meeting are aware that the family will be attending.

The multi-agency review meeting

The Chairperson would lead introductions, setting out the purpose and expectation of the meeting, agreeing the agenda, and placing the emphasis on what can be learnt to improve services. The chairperson would normally be the local reviewer but may in exceptional circumstances be the Local Area Contact or peer reviewer.

The Chairperson would facilitate discussions focusing upon key questions identified. They would ensure that all are able to contribute to the meeting, by being mindful of:

- The use of jargon and terminology.



- The emotions of people in the room.
- Allowing sufficient time for everyone to speak.

At the end of the meeting it should be agreed how families will receive feedback where required.

Questions and Answers

Will families automatically be informed of the review process even if they haven't had involvement with the person who has died for a long time?

Not necessarily - it will be up to the reviewer to make the decision based upon the information that they have gathered during the review. However it would be useful to consider how the family might feel if they are not told and to bear in mind that – on rare occasions – providers may tend to play down the involvement of families where there have been differences of opinion about services provided.

What happens if the person who has died has indicated that they don't want their family involved in their care?

Reviewers should try to explore the context of why and when the person who has died indicated this and make a decision based upon the information they receive. If for example, there have been ongoing safeguarding issues with the family, it may not be appropriate to include them in the review process. If on the other hand the comment was made and recorded some years ago and the family have been involved with the person more recently, you may feel justified in putting this aside in order to gain additional learning.

How can a reviewer prepare if they think that a family has a “difficult to deal with” reputation?

The review should be a fresh situation with someone the reviewer has not already worked with. The reviewer is expected to approach each review professionally with an open mind, giving the relative no reason to feel prejudged but remembering how they may have felt when others have had preconceptions about them or their role. Reviewers should:

- Be aware that many families have had to fight to get and improve health or care services for their family member and may well have a legitimate sense of injustice or been alerted by media exposure of bad practice.
- Ask families how things could have been done better in the context of learning.
- Reinforce the purpose of the meeting.
- Be confident they have details of others who will support relatives beyond the review (for example to make a complaint or process their dissatisfaction or grief).
- Remember that the emphasis of the reviews is on service improvement. Reviewers should steer conversations to what could have been done differently and how services could learn from the experiences of the family.

What does legislation and guidance say about me talking with families?

Section 11 of the Health and Social Care Act 2001 places a duty on NHS organisations to make arrangements to involve and consult patients and the public in:



- Planning services that they are responsible for.
- Developing and considering proposals for changes in the way those services are provided.
- Decisions to be made that affect how those services operate.

Therefore, at national, regional, commissioning and service provider level, users and carers should be actively involved in planning, delivering and evaluating service provision. The overall aim of Section 11 was to increase patient-centred care and improve the users and carers experience by ensuring they are involved at the beginning of any process to develop or change services.

The NHS England 'Commitment to Carers' (2014) guidance echoes the requirements of the Care Act to place carers centrally in any consideration of a person's care. In addition, it sets out the need to review existing processes to gather bereaved carers' views on the quality of care provided to their relative in the last three months of life in order to help address gaps in evidence.

The NHS Constitution (2015) states that NHS services '*must reflect, and should be coordinated around and tailored to, the needs and preferences of patients, their families and their carers*'. It goes on to stress that staff should '*be open with patients, their families, carers or representatives, including if anything goes wrong, welcoming and listening to feedback and addressing concerns promptly and in a spirit of co-operation.*'

Further information

NHS England (2014) 'Commitment to Carers'. Available from: <https://www.england.nhs.uk/wp-content/uploads/2014/05/commitment-to-carers-may14.pdf>

National Quality Board (2018) National guidance for NHS Trusts engaging with bereaved families. <https://www.england.nhs.uk/ourwork/part-rel/nqb/national-guidance-for-nhs-trusts-engaging-with-bereaved-families/>