



The
University
Of
Sheffield.

Communicating a diagnosis of mesothelioma: Findings and Recommendations from the Radio Meso study

Taylor B, Tod A, Stanley H, Ball H, Warnock C.

May 2018

Acknowledgements

We are grateful for the funding for this study, from Mesothelioma UK.

We also extend a huge thank you to all the participants of the study. Their generosity in sharing time and experiences was invaluable. The learning this allowed was essential in completing the project. We would also like to thank those who responded to the consultation, patients, family carers and specialist nurses. These comments were vital when testing and finalising the recommendations.

We would like to thank all those who supported and advised on the study, including Liz Darlison and Lorraine Creech, and others from Mesothelioma UK. The specialist nursing and communications teams have provided invaluable help throughout the study. Without their help this study would not have been possible.

For further information please contact Mesothelioma UK or the RADIO Meso Research Team on the links below:

Mesothelioma UK: info@mesothelioma.uk.com +44800 169 2409

RADIO Meso: Angela Tod, a.tod@sheffield.ac.uk +44 114 2222057

Communicating a diagnosis of mesothelioma: Findings and Recommendations from the Radio Meso study

“We need to make the patient feel like the most important person in the room”.

Introduction

Communicating a diagnosis of mesothelioma, is a complex and highly skilled activity.¹ If done badly ‘it can cause long lasting distress, confusion and resentment’.^{2, 3} There is a lack of evidence on how best to communicate a diagnosis of mesothelioma.⁴

A recent research project, the Receiving A Diagnosis Of MESOthelioma (RADIO Meso) study aimed to address that gap and build on previous research^{1,3,4} RADIO Meso was funded by Mesothelioma UK. The project aimed to understand how the mesothelioma patient and carer experience of receiving a diagnosis could be improved and to generate recommendations for practice.

These recommendations have been endorsed by Mesothelioma UK and are summarised below. Quotations from patients, family members and health professionals who took part in the RADIO Meso research study have been included. These illustrate what can work well, and provide exemplars of practice that gave rise to concerns. The recommendations have been developed to be used by health professionals involved in communicating a mesothelioma diagnosis. We recognise that healthcare staff often work within resource constraints such as time, environment, and staffing. This will sometimes impact upon the ability to achieve best practice. However, these recommendations provide guidance that has been derived from patient, carer and healthcare staff experiences. They are aspirational and summarize factors that can influence good communication.

The recommendations focus on the time at which diagnosis is confirmed, but it is important to remember that other bad news can be broken to patients and carers at many points along the diagnostic and care pathway. For example if people are informed that they are not eligible for a particular treatment or research trial that hope had been invested in. These recommendations apply to communication at all those points that bad news is broken.

“Although it was devastating it was actually told to us very well”.

10 top tips for communicating a diagnosis of mesothelioma

Summary

1. Provide **consistency and continuity** in terms of who the patient sees and what is said.
2. Involve the **Clinical Nurse Specialist** throughout, starting as early as possible in the diagnostic pathway.
3. Ensure that staff involved in communicating a diagnosis of mesothelioma have **specialist knowledge and training** in mesothelioma, as well as communication skills. Training should be ongoing with access to regular updates.
4. Be **patient-centred** when communicating a diagnosis. Take cues from the patient and family in balancing what information to give and when. Use language that is easy to understand. Don't just rely on written information and booklets.
5. **Prepare and plan** as a team before communicating a diagnosis of mesothelioma. This should include the communication of a plan for ongoing management and treatment to the patient and family carer.
6. Provide a **quiet and private environment** to facilitate communication.
7. Ensure the patient feels they have been allocated **sufficient time**.
8. Be direct and honest whilst **maintaining hope** where possible, for example by providing information about appropriate treatments, symptom management and trials.
9. Use available **expertise and resources**. No single clinician should carry the responsibility of communicating a diagnosis on their own. Best practice is often from partnership working with different services and quality resources.
10. **Make the patient feel like the most important person in the room**, and at the centre of the communication process.

Recommendation 1. Continuity and consistency

A diagnosis of mesothelioma may be confirmed at a specific appointment, such as an out-patient clinic or on a ward. However, communicating that diagnosis is a process that happens over time. The process starts when mesothelioma is first suspected and continues on to treatment, as people start to understand their diagnosis and its implications. If a diagnosis is to be communicated well, this process should provide continuity and consistency in terms of who the patient / family see, and what is said to them. The Lung Cancer Nurse Specialist (LCNS) can be key to ensuring continuity and consistency and making sure information provision to the patient / family is managed in a co-ordinated way.

Follow-up appointments after key points in the pathway, for example a mesothelioma diagnosis is confirmed, emerged as a key element of care continuity that enhanced communication. This enables families to digest initial information and then the *'101 questions that emerge after'*. The LCNS has the skills and knowledge to provide this follow-up, but resource is required to enable it to occur.

"the doctors wouldn't really talk about compensation, and attendance allowance, practicalities to do with the home, you know, the OTs, the physios, the palliative care nurses. That's a conversation that we usually have afterwards" (LCNS10)

"So, all I can say is, I knew, I think for me, and the most expert form of contact was the specialist meso nurse. And I knew that she would be there, she told me, she'd be on the phone, and I could ring her anytime". (MM4W)

"They're still accessible on the telephone, even now, I wouldn't hesitate to ring up one of the nurses or the [SPECIALIST] nurse, and I know she'd talk to me, now even afterwards". (MM4W)

"There's the specialist nurse. I've got her number, and she's always said never hesitate to contact me". (MM9)

"I could relate to the doctor, obviously, but I knew the nurse was the one I was going to be relating to. So it was appropriate that I sort of got to know her, because mostly it's by telephone" (MF2)

"I always see somebody completely different. Never see the same person". (MM1)

"I think the pre-work you do, as in what you do in that first consultation, the support you give them during the test and the results, and on the day you get the results. The ones where I feel it's very different and where we don't have an input or an impact is the inpatients. So somebody who might have presented on a Friday tea time to either A&E or a medical admissions unit with shortness of breath, some kind of tests are done, but they're sent home. So we're not aware of what they've been told or what their expectations are. You might meet them for the first time at diagnosis....that's more difficult when you've not got that relationship, when you've not got established contact and careful communication. And they often have quite ad hoc information, because these are more junior staff usually on a weekend, as in not experienced in mesothelioma". (LCNS2)

Recommendation 2. Mesothelioma or Lung Cancer Nurse Specialist

The continuity provided by a LCNS has the potential to improve the quality of the diagnosis experience for patients and family. The relationship that develops between the LCNS, the patient and family members can help them anticipate communication needs. Local systems need to be in place to ensure the CNS is informed as soon as a mesothelioma diagnosis is suspected, whether the person is an inpatient or outpatient.

The LCNS can manage the communication across the diagnostic pathway and between the multi-disciplinary team members, for example, explaining what is happening and why regarding diagnostic procedures, tests and appointments and track progress through these.

“I do remember my mum and dad commenting that it was just a horrible experience, the way it all happened.... And it was almost that feeling that we didn't actually want to go back and see that doctor. It was just the way it was all handled. It just wasn't really nice.... Then, we went in to see the nurse and she took us in and it was much more...just a much more human approach, I suppose....” (MM3D)

“The doctor that gave me the diagnosis, she works in the respiratory section, and she was the one who was obviously monitoring the fluid, and she asked me to go and see her about having a...what do they call it? A tube into my lung. And when I went to see her about that the nurse was there as well, and that was good. And then I asked lots of questions”. (MF3)

“And I do think as a nurse, especially because we get to know the patients as a person, not an illness, and I think it's our role to be their advocate and to fight their corner”. (LCNS7)

“We're the ones who have the patients ringing us saying oh my god have they still not got a date for that test or investigation and 'where's my biopsy, you promised ...you told me it would be soon and now I haven't heard and it's two weeks, three weeks, what's happening'? And we're the ones who constantly are saying sorry as well or 'listen we'll try and get it...we'll see if we can do anything better than that date'. We're constantly trying to be their advocate. (LCNS1)

“Honesty I think is very important, so being able to answer patient's questions truthfully”. (LCNS8)

Recommendation 3. Training

Staff involved in communicating a diagnosis of mesothelioma should have appropriate knowledge and training to ensure they have the confidence to conduct the task well. This includes:

1. Specialist mesothelioma knowledge to enable staff to clearly explain the condition, pending procedures, legal and financial implications as well as treatment and clinical trial options.
2. Communication skills, using appropriate language and avoiding medical jargon. The way information is communicated is as important as the words used. Skills valued by patients in RADIO Meso include the ability to communicate in a warm, inclusive, respectful and participatory manner.
3. Regular training updates are needed to support ongoing development of mesothelioma knowledge and communications skills, and ensure up-to-date knowledge of staff.
4. Opportunities for supervision, reflection and learning from others are positive supplements to formal training.

“She [the doctor] just flung those words at us, incurable cancer...said it as quick as she could almost, incurable cancer, three and a half years, more or less. That was it. I sort of think she waited for us to say something but, frankly I think we were both in shock. Then, my husband did repeat it. He said, are you telling me I’ve got incurable cancer and she said yes. That was more or less it then. There was a long silence and nobody said anything. I think I was in a state of shock. It’s the incurable that gets you”. (MM7W)

“I mean her body language was very good; you know, she faced us head on, she didn’t look away, it was eye to eye contact. The Specialist Nurse was in the room with us as well, and they were behind us with their hand on our shoulders. It was the best it could have been, if you know what I mean”. (MM10W)

“I’ve done the communications course, the advanced communication course. I did that in my previous role But all the specialist nurses at the time did that and I think everybody has...most people have done it.... they still run them here periodically but they only allow you to go on it if you’ve never had communication training advanced. I feel that all...the refresher would probably be good”. (LCNS1)

“I had personal clinical supervision, which I pay privately for, because I was recognising in this job you need to have someone to talk to There was talk about the advanced communication skills training was going to be kind of every three years, to be an update day, but that never happened, which is a real shame, because I think that would have been invaluable, really”. (LCNS7)

“My colleague who’s been here six years said I’d like to come in and sit and watch what you do as well. All of the consultants said I think you should do that, I think they need to see what you all do differently. And you learn from each other”. (LCNS2)

Recommendation 4. Be patient-centred

Patients and their families report that being given a diagnosis of mesothelioma is often shocking and distressing. People vary tremendously in the amount of information they want to know and are able to assimilate. It is therefore important to be patient-centred when communicating a diagnosis, flexible in information provision and skilled in balancing what information to give when. Being skilled at listening, assessing what people know already, taking cues from body language and gauging people's response to information will help identify what is appropriate to say, when and how. For example, there is sometimes a temptation for clinicians to feel they have to 'go through everything' at the point of diagnosis. However, if someone is upset or shaken by diagnostic information, it may be better to summarise key points and plan a follow-up session. It is important to avoid people feeling overloaded with information. The CNS is often best placed to plan and deliver that follow-up.

Personalising the diagnosis will require tailoring communication for individual patients and family carers. This will entail listening carefully, using language that each patients and family carer can understand, and avoiding unnecessary medical terms and technical language.

Broadening out from a patient-centred approach to a relationship-centred approach is important (See Appendix 2 for further information and explanation). For care and communication to be therapeutic, value is placed on enhancing relationships between all those involved (patient, family carer and health staff).^{7,8}

"I certainly didn't understand mesothelioma at all really. ...although I was going to say I looked it up on the internet, initially I don't think I did anything because I was a little bit taken aback and there was quite a bit of shock and upset and we didn't know really what to do, if the truth is known. And that's unusual for me because I would normally grasp it right away and be in control of it, but I wasn't". (MM1)

"I didn't want to know how long if it was only going to be a few months. My daughters were with me at one of the first times we went to see Dr [name]. One daughter, I think she had the feeling maybe I did want to know, she started to say something and I said, oh no, no, I don't want to know. I couldn't bear the thought of being told only six months. You know, the 12 months was bad enough. I can live with three and a half years, but oh, 12 months or any less is unbearable". (MM7W)

"And again, with the doctors, obviously they'll tell you the information that you want to know, and obviously they have to be quite open and quite poignant, but I must admit sometimes I used to wait until my mum and dad had gone, and then actually I would say to them, sort of, okay, now can you be honest with me. 'Cause obviously my mum was so positive that she was going to get through this, but I don't think she really had the true understanding of the severity". (MM5D)

"So she was able to explain a lot of it and she used drawings and pictures and things to show me because I hadn't even got a clue, I didn't know anything about lungs". (MM6D)

“Continuously going over the same ground, the same conversation and that you may go through everything with them and then at the end of the conversation they say, well I can't quite believe I've got this, have I really got this”. (LCNS1)

“[We are] very much guided by what they want. So you're sat in that room with a relative usually, or two, and the patient. They usually all want to know varying degrees of information, from the thread to the needle. Some wanting to include prognosis, some not. And I think that's the skill of our job, if there is a skill, which we need to very much gauge it to that audience and the information and the level you give”. (LCNS 2)

Recommendation 5. Be prepared

If communicating a diagnosis of mesothelioma is to be conducted well it needs to be planned for. Planning needs to occur at a patient and team level.

Planning strategies that can help the patient:

1. Make sure the CNS can meet and get to know the patient/family as soon as possible in the process. This means they will have an understanding of how best to prepare them for the diagnosis.
2. Check what the patient's understanding is about mesothelioma throughout the process. Don't assume they understand.
3. Be aware of the individual family and social context within which the diagnosis is being delivered. For example, establish as early as possible the level of family and social support available.
4. Ring the patient before the first diagnostic clinic appointment and explain what is going to happen and why.
5. Give a 'warning shot' that is, make sure people know as soon as appropriate that mesothelioma is one of the conditions that is being investigated as a possible diagnosis.
6. Make sure patients and family carers have a clear plan communicated for the future. This will include the plan for ongoing tests and investigations prior to a diagnosis being confirmed, and a plan for treatment and care, after diagnostic confirmation

"That was a great, kind of, morning. It was really, kind of, a one stop shop.... I mean, she was absolutely fabulous. ...having a specialist [nurse] in the room at the same time, 'cause he had the diagnosis. But, I mean, that was...it was really, really, really helpful actually". (MF2)

"I really do think that the family should be informed and be prepared for that worst case scenario. I know you don't want to scare people and I know some people are different, but I do feel the fact that we were asking the questions, the information should have been a bit more forthcoming, to be prepared for that news". (MM3D)

"So when the consultant said...and they were very kind, the consultant told them, he took my dad's hand and said, you need to make sure that you take whatever treatment that we offer you. But they obviously couldn't confirm it until he had the thoracoscopy, but they came away thinking it's likely to be cancer" (MM6D)

"One of the big things that were missing was communication between all the services, effective communication..... It was my mum phoning the doctor who initiated everything else, but by that time it was almost too late. It was like everything was being rushed. And my biggest criticism is that there should have been a plan right up front that my mum and dad should have been involved in". (MM11D)

"What we hope is that when we've seen them initially you've led them to believe this might be it, and it's a continued relationship to make sure it's not too surprising" (LCNS2)

“So they come to the clinic, see the consultant, are usually told at that appointment that this is suspicious, we think that it looks like mesothelioma, explain what it is. It’s all done very gently”. (LCNS3/4)

“I think it’s important that people are aware when they’re investigating that they may have a cancer, because it gives people time to process”. (LCNS8)

“There’s no hidden agenda, what I know is what you know, we’re all on the same page, going forward. This is the plan. So what we’re going to next is X Y and Z, you know, and then we’re going to review you and see how you go”. So, for me, it’s about making sure the patient comes in and they go away with a plan and they’ve got contact numbers, they know how to get hold of you and they know what to do if you’re worried and their relatives know what to do if they’re concerned and if necessary, I’m mobile, I see them in the community to support them’ (LCNS11)

Planning strategies that can help the team:

1. Make sure the patient has been discussed in a Multi-disciplinary Team (MDT) meeting and treatment options agreed prior to the confirmation of a diagnosis. Specialist Mesothelioma MDTs can help streamline planning regarding diagnosis as well as treatment/trial options.
2. Make sure you have all the key facts in front of you for any key appointment or discussions with patients and family about the diagnosis. For example, have relevant information assembled before the appointment, the patient history, family circumstances, test results and what they already have been told.
3. Get appropriate information resources ready to give to the patient and family (e.g. relevant information sheets, scans, pictures). This means drawing on a range of information resources in a timely manner, ready to give to patients and family members in line with individual preferences.
4. Prior to the appointment when the mesothelioma diagnosis is confirmed, plan how you are going to manage that communication. If a Doctor and CNS work together in a planned way communication is enhanced. It is then clear what is going to be said, who is going to cover what. Any follow-up communication by the CNS can also be anticipated and planned.

“It [specialist mesothelioma MDT] will help with the quality of discussion around the management plan” (Doctor 1)

“I did see the specialist nurse later and she arranged for me to see the oncologist because I’d been put in the wrong clinic. It was a catalogue of disaster, it really was. And she was very supportive. She suggested I went home and fetched my wife, told my... Because I didn’t tell my wife for about a month. ...The nurse suggested I went home and told my wife and brought her back, and she arranged for the oncologist to come in early for me to see her. We sat with the oncologist, the nurse was with us, and I’ve got to say she’s been amazingly supportive ever since (MM9)

“The thoracic nurse spent quite a bit of time with me while... and then my daughters spoke to the doctor, to get the information because I wasn’t able to take it in”. (MF1)

“We’ve got excellent consultants that are really good at breaking bad news. So in the past we’ve had consultants that haven’t been good at breaking bad news and that is what makes the difference. It’s how that’s done. Because that person’s life is changing forever, and how that is portrayed to them is so important. So I think we are very lucky in that. We don’t have to pick the pieces up from bad communication, which I have done in the past, but we don’t anymore. We’ve got a really good team”. (LCNS1)

“Make sure that you’ve got all your facts in your head or in front of you clear, so that you’re not going to be bumbling through it, so you’re clear before the patient comes in the room, you’ve got all your facts in front of you, clearly sorted in your head, so you know exactly what the diagnosis is, what the treatment plan roughly is, who that’s going to be with and how you’re going to organise all that for that patient, and that you have all the patient information stuff ready to give them”. (LCNS7)

Recommendation 6. Environment

Having an environment that is quiet and private will facilitate challenging communication such as a diagnosis of mesothelioma. For example rooms should ideally be big enough, with enough seating for family members, and not be dark and gloomy. Clinic or ward areas where a conversation can be overheard or disturbed by surrounding clinical conversations can make diagnostic communication more difficult for everyone. Sometimes it is difficult to achieve these environmental requirements in busy, pressured clinical environments but privacy and comfort should be protected where possible. Strategies that help include the following.

1. Use of door signs/magnets in clinic or curtain clips on wards to indicate a conversation should not be disturbed.
2. Scheduling a diagnostic clinic appointment at the end of clinic when there is more chance of noise being reduced. This also offers people some privacy as, if distressed when leaving the consultation room, they won't have to walk through a busy clinic.
3. Have a quiet neighbouring consultation room in for the CNS to take the patient and family after the diagnostic appointment so they can offer follow-up care, support and information.

“But we were just took in a small little room, I don't even think there was enough chairs for us to sit on, and told it's mesothelioma, which we couldn't even say, let alone know what it was, and basically, you know, it's incurable, there's nothing you can do, it varies in different patients, gave us this booklet, or pamphlet, with leaflets in”. (MM1D)

So we then went back to the waiting room and were taken into a small room really where there was a bed or where you could lie down, and we waited in there. Then after a few minutes the surgeon came in with a lung nurse, who I didn't realise who it was at the time, and said that you have mesothelioma and basically we'll refer you to an oncologist, and there's nothing really we can do..... It sort of took us all back really. We were in this little tiny room and it was quite hot and the surgeon and the nurse left the room, as far as I recall, and we were left on our own looking at each other thinking what happens next”. (MM1)

“But when you're sat in a waiting room knowing there's something wrong with you but you don't know what and you've got all these posters around you about lung cancer it's not nice really”. (MM2D)

“We're often put in what would probably be an examining room, one that particularly has no window, it's very small. You usually have to sit a couple of relatives on the couch and you in the... I had one man pass out once. Obviously the shock of it and everything, and there's no window, there's no air in there”. (LCNS2)

“We aren't well resourced, but we do insist that we have a room at the clinic. We have to battle when we go into the clinic to get a room, but we do insist that we have that room, so they and us one. But it isn't well resourced, to be honest. It's a bit of a battle before the clinic starts”. (LCNS3/4)

*“I sometimes think it would be lovely if we had a room where it wasn't in the main outpatients where they were then having to leave that room and walk back down past people waiting to come into clinic. I just wish it was you could bring them in one way and then they could leave through a back door kind of thing, or a door where it's private and they can just go out and get to the car or go for a cuppa or you know what I mean”
(LCNS7)*

Recommendation 7. Time

Allocating appropriate time, and creating a sense of time, are both essential to good communication of a mesothelioma diagnosis. Allow sufficient time for the appointment when the diagnosis is confirmed, whether at an out-patient clinic appointment, or on a ward. The recommendations are to:

1. Allow at least an hour.
2. Protect that appointment time to prevent being interrupted.
3. If in clinic allocate the diagnostic appointment at the end of clinic to ensure no disturbance from other clinic activity.
4. Allow time for preparation by the doctor and CNS prior to the patient's appointment to agree what communication and clinical options to use to enhance the diagnosis communication.
5. Allow time following the appointment for reflection on what went well and what could have been done better.

"I felt that there was a lot more that could have been done at that initial time you're really left to go away and wait for an appointment. Certainly [I would have liked] a longer appointment". (MM1)

"They were very, very good. Time was no object, really, to them, if they could fit it in, and they'd answer all my questions". (MM4W)

"But my mum and dad were in complete shock, they were then taken to see.... But I think they were in such a state that they didn't take a lot in and that was part of the problem, we think that that maybe happened too quickly". (MM6D)

"And it's brilliant, and he talked to us, he spent fifty minutes with us going through the x-rays. And, I mean, one of his interests is Mesothelioma. So, he was brilliant with us" (MM11D)

"Give yourself and the patient time to do it in a non-rushed setting.... when they would come back for their bad news, I would probably spend three-quarters of an hour with each patient, minimum, because I was able to explain the results to them, and then talk through any questions or worries they'd got, and go through any symptoms and everything, and really just take my time, give them the time and just feel like when they'd gone out that they'd got everything they needed from me without feeling they were holding a clinic up". (LCNS7)

Recommendation 8. Hope

Be direct and honest whilst maintaining hope. Although a mesothelioma diagnosis can be a shock and devastating, there is potential to balance out upsetting news with the positive. Certain strategies that help with this include the following.

1. Finish a diagnosis conversation with a positive point, for example potential treatments options, a plan for future management
2. Ensure that patients/family leave a diagnostic appointment with a clear plan of what is going to happen next regarding clinical management.
3. Emphasise that whilst mesothelioma isn't curable, there are treatments and good symptom management available.
4. Know what treatments and trials are available and ensure people are offered whatever is appropriate for them.
5. Help set goals to improve quality of life.

“How you talk about mesothelioma started to become more of an issue for me.... you've gone to see somebody for hope actually.... and I'm in the situation...you want to get some hope and something that improves the situation that you're in. I guess some people may be prepared for [bad news], but I'm just like, oh my God. And actually you don't really need to somebody to say to you, like, how horrendous it is! You know that”. (MF2)

“So I saw the oncologist again before the surgeon and...I mean, actually he was great in that he was very pragmatic and then none of this nicey, nicey, I'm so sorry, blah, blah, blah. I think he was just like, okay you've mesothelioma, now we're going to talk about what we're going to do. Which is totally what I needed.... I mean, he wasn't, kind of, setting anything up to be less than it was, like, he was just much more, kind of, pragmatic and practical I think. Didn't say the word 'palliative', thank God. And then talked about treatmentI'm young and female. I know that these things will give me...are likely to give a better outcome”. (MF2)

“You know that. “She didn't say 'you've got this and that's it'. She said 'you've got this and this is the options, from radical surgery, there is chemotherapy ... So even though it was disastrous news in many respects, she gave us a list of things that, you know, like there was a plan around what would happen, as opposed to 'you've got a terminal illness' and that's it. You know, there was a plan.” (MM10W)

“I think letting them know exactly what you said, that the MDT, it's just not our decision, these things are discussed with the experts who do the treatmentI think reassures patients when you let them know that”. (LCNS7)

“Lots of people see having treatment as a benefit. But we'll always try and offer hope. So even if that hope is about really good palliative care and really good symptom control and about making life choices even though that life may be short, we try and offer hope within the consultation, and we don't want to leave it on a doom and gloom... Obviously you've given bad news. It's not nice. But I always try my best to offer some kind of hope there”. (LCNS2)

“And so, you know, we live in hope. MM10 is 68, we want to get him to at least 70, so that means he’ll have had the disease three and a half years. So that’s, kind of, we’re setting little goals out for ourselves all the time, doing things and trying to enjoy things that we’d never done before – like go and visit a test match.... doing nice things, creating magical memories I’ve been calling it. Everywhere we go, taking pictures and spending more time with our grandchildren, spending more time with [husband’s] brother and my family. We’ve got a family gathering this weekend, everybody here for a bit of a buffet and stuff. I think it’s just about creating memories all the time”.
(MM10W)

“I think it’s important for us to be honest and to try not to be too bleak but also not to overestimate either, so it’s very hard to get that balance, because you obviously don’t want to hurt somebody, you don’t want them to be feeling like there’s no point to anything, but it’s getting that balance”. (LCNS7)

Recommendation 9. Use available expertise and resources

No single clinician should carry the responsibility of communicating a diagnosis on their own. Best practice is often from partnership working, referring to different services and using good quality resources. The following approaches are helpful:

1. Refer to practitioners and services as appropriate in order to use the expertise of others. For example, Asbestos Advisory Services/Groups are often best placed to advise on benefits, compensation and legal claims. Some patients may also benefit from timely referral to palliative care and counselling services.
2. Use the resources available from specialist organisations to ensure up to date and good quality, accessible information and support. Examples include the information resources and telephone helpline developed and delivered by Mesothelioma UK.

“The specialist nurse took my wife into the office and sat her down, and she was obviously very upset. She gave her advice on where she could gain counselling and so on. She was very good”. (MM9)

“So, the lung cancer nurse, she was really good, she got me in touch with [Asbestos Support Charity] ... and they helped with filling out some DHSS forms, and things and that”. (MM8)

“I rang Mesothelioma UK a couple of times for information, the first time I rang them was after [the diagnosis]I rang them really to just get their take because when you type mesothelioma into Google the first thing you get is all the ads from all the legal people which I didn't want, I didn't want any sharks. And I rang them for some sort of advice about what my dad was entitled to and just to get it straight in my head, and they were very helpful” (MM2D)

I then went along to the [asbestos disease support group] group for the first time. I heard about their coffee morningsI thought I'll go along, but the idea of a coffee morning isn't my cup of tea, but it actually was very good. Very good. Very helpful for my wife. Very encouraging for me, because there was 20 plus people in the room, all in the same boat, mainly couples, and I think virtually all of them were at least 18 months into their diagnosis: ...so suddenly that lifted me. There is more hope”. (MM9)

“We've also got an asbestos support group which as soon as they've got their diagnosis we give them information about that”. (LCNS3/4)

“We give them information about solicitors, and about all the local asbestos support groups in this area, there's information on counselling, on Macmillan, grants, on everything, citizen's advice, dietician.... they have the card of Mesothelioma UK inside their pack as well, and I always tell them that there is a specialist nurse attached to them who can talk to them. I always advise them to get in contact with a solicitor in the first week of diagnosis.” (LCNS6)

Recommendation 10. Make the patient feel like the most important person in the room.

Communicating a diagnosis is challenging. Each patient will vary in terms of the timing, content and mode of information delivery. Tailoring communication to the individuals needs is vital. Fundamental to this is the patient feeling that they are at the centre of the communication process. If they feel that they are the most important person in the room, they are more likely to access ongoing support and information to meet their needs across the diagnostic pathway.

“One of my concerns was that my dad had somebody to talk to about any fears or worries, et cetera, because my mum was only just managing to hold it together whenever she was with him and they didn't seem to want to have any conversations about what was actually happening. So then I was worried that if he wanted to talk to somebody was he having that opportunity or if he had questions, et cetera. So I'd spoken to the Specialist Nurse about that on the phone and she made a point of going and talking to him and things and giving them that opportunity to talk about stuff if he wanted to. But I think that was important as well”. (MM6)

“And obviously all I can say, now, from there, is that the help and attention, and love and care we've had through things, has been brilliant, it's been really very, very good, from all.... But it was just the immediate reaction of, you know, do you understand, the shock...” (MM4W)

“It's an honour almost...sounds a bit corny, but it's an honour to do it. It's a very important time in that patient's life and their families and they're never going to forget it, and you can actually change the way they feel about things. You can make a difference, hopefully, a little bit of a difference that makes things a tiny bit easier for them. You just hope that that's the difference you make”. (LCNS2)

Conclusion

The recommendations presented here are based on the experiences of patients, family members and health professionals who participated in the RADIO Meso research study. They have also been informed by a wider consultation. The aim is that these recommendations will provide some guidance and support to health professionals.

References

1. Ball H (2013) Are the psychosocial needs of patients with mesothelioma the same as those with advanced lung cancer. Masters Dissertation. Faculty of health and Social Care. London South Bank University
2. Warnock C (2014) Breaking bad news: issues relating to nursing practice. *Nursing Standard*. 28, 45, 51-58.
3. Warnock C, Tod AM, Foster J, & Soreny C. (2010) Breaking bad news in inpatient clinical settings: role of the nurse. *Journal of Advanced Nursing*. doi: 10.1111/j.1365-2648.2010.05325.x
4. Fallowfield & Jenkins (2004) Communicating sad, bad and difficult news in medicine. *The Lancet* 363, 312–318.
5. Richie, J and Lewis J (2014) *Qualitative research practice: a guide for social science students and researchers*. 2nd Edition. London: Sage.
6. Ritchie J, Spencer L. (1994) *Qualitative Data Analysis for Applied Policy Research* In: Bryman A, Burgess G. (eds) *Analysing Qualitative Data* London. Routledge. pp 173-194.
7. Nolan M, Davies S, Brown J, Keady J, Nolan J. (2004) Beyond 'patient-centred' care: a new vision for gerontological nursing.
8. Nolan M, Brown J, Davies S, Nolan J and Keady, J (2006) *The Senses Framework: Improving Care for Older People Through a Relationship-Centred Approach*. Getting Research into Practice (GRiP) Report No 2, University of Sheffield.
9. Nolan, M., Davies, S. and Grant, G. (eds) *Working with older people and their families: key issues in policy and practice*. Open University Press, Buckingham, P175

These recommendations have been developed by the RADIO Meso research team in consultation with Mesothelioma UK

Appendix 1: Participants in Radio Meso interviews

Table 1. Radio Meso Patient and Carer Interview Participants

| | | |
|----------------|-------|---|
| Participant 1 | MM1 | Man with mesothelioma |
| Participant 2 | MM1D | Daughter of participant 1 (man with mesothelioma) |
| Participant 3 | MM2D | Daughter of a man with mesothelioma |
| Participant 4 | MM3D | Daughter of a man with mesothelioma |
| Participant 5 | MF1 | Woman with mesothelioma |
| Participant 6 | MF2 | Woman with mesothelioma |
| Participant 7 | MM4W | Wife of a man with mesothelioma |
| Participant 8 | MM5D | Daughter of a man with mesothelioma |
| Participant 9 | MM6D | Daughter of a man with mesothelioma |
| Participant 10 | MM7W | Wife of a man with mesothelioma |
| Participant 11 | MF3 | Woman with mesothelioma |
| Participant 12 | MM8 | Man with mesothelioma |
| Participant 13 | MM9 | Man with mesothelioma |
| Participant 14 | MM10W | Wife of a man with mesothelioma |
| Participant 15 | MM11D | Daughter of a man with mesothelioma |

Table 2: Radio Meso Staff interview participants

| | |
|---------|---|
| LCNS 1 | In a team of 2 LCNSs at an NHS Hospital Trust in a town. In post 3 years. |
| LCNS 2 | Single handed LCNS in large NHS Hospital Trust in a city. Just awarded funding for additional LCNS post. In post 12 years. |
| LCNS 3 | One of three LCNS in the team in an NHS Hospital Trust serving rural/town area. In post 3 years |
| LCNS 4 | One of three LCNS in the team in an NHS Hospital Trust serving rural/town area. In post 12 months. |
| LCNS 5 | One of two LCNS in the team in an NHS Hospital Trust serving rural/town area. In post over 18 years. |
| LCNS 6 | Single handed LCNS in an NHS Hospital Trust serving sea side town. In post 3 years. |
| LCNS 7 | Single handed LCNS in an NHS Hospital Trust serving rural area. In post 17 years. |
| LCNS 8 | In a team with 3 other LCNS in large NHS Hospital Trust in a city. Just awarded funding for additional LCNS post. In post 14 years. |
| LCNS 9 | Single handed LCNS in an NHS Hospital Trust serving rural area. In post 10 years. |
| LCNS 10 | LCNS in an NHS Hospital Trust serving rural/town area. In post 17 years. |
| LCNS 11 | LCNS in large city NHS Teaching Hospital Trust in a team of 1.5 LCNSs. Works with 1 additional half time LCNS. In post approximately 5 years. |
| LCNS 12 | LCNS in large city NHS Teaching Hospital Trust in a team with two other LCNSs. In post 13 years. |
| LCNS 13 | LCNS in large city NHS Teaching Hospital Trust. Trust covers two sites. LCNS 13 covers one site. In post 18 years. |
| LCNS 14 | LCNS in large NHS Teaching Hospital in a team of 3 LCNSs. Been in post >20 years. |
| D 1 | Respiratory consultant in NHS Teaching Hospital Trust. <3 years in post. |
| SW 1 | A Support Worker in a team of three LCNS in an NHS Hospital Trust serving rural/town area. In post < 3 years. |

Lung Cancer Nurse Speciality = LCNS, Doctor = D, Support Worker = SW

Appendix 2: Relationship-centred care: The ‘Senses Framework’

Previous research into care of older people has identified that the best care environments promote relationship-centred care. This approach enables all participants involved in giving and receiving care to experience six ‘senses’. That is, they should be able to experience a sense of security, belonging, continuity, purpose, achievement, and significance. These six senses have been referred to as The Senses Framework.⁷

It was also proposed that where relationship-centred care is valued and the Senses Framework is implemented, an enriched care environment is allowed to flourish.⁸ The data from the RADIO Meso study indicate that effective communication occurs if a relationship-centred approach is adopted. In this way patients, family carers and staff are able to experience the six senses, despite the fact that the news that is communicated can be unexpected and disturbing.

The Senses Framework in the context of effective communication of a mesothelioma diagnosis

Security

Patients and family carers: To feel safe and confident that communication and care will be competent and sensitive.

Staff: To feel confident in knowledge and ability to communicate a mesothelioma diagnosis effectively, with the appropriate working relationships and resources.

Belonging

Patients and family carers: To feel part of things and be able to maintain and form meaningful relationships with members of the care team to enable good quality communication regarding diagnosis.

Staff: To feel part of a team with shared values and approaches to diagnostic communication, and where each person's contribution is valued.

Continuity

Patients and family carers: To experience seamless and consistent communication and care that recognises personal experiences and life contexts. To experience links, connections and ongoing relationships with people involved in communicating diagnosis and providing care.

Staff: To have clear standards and shared expectations with colleagues regarding diagnostic communication.

Purpose

Patients and family carers: To be able to identify and pursue goals in relation to the mesothelioma diagnosis including treatments, trial opportunities and wider priorities in life.

Staff: To have a sense of care priorities related to diagnostic communication and goals regarding care that each member of the team are aspiring to achieve.

Achievement

Patients and family carers:
To be able to discuss and plan ways to achieve goals that have been set and make progress towards achieving them.

Staff: To be able to provide good care and communicate effectively, feel a sense of achievement and contribute to the achievement of therapeutic goals as appropriate.

Significance

Patients and family carers: To feel recognised, valued and involved during communication regarding a mesothelioma diagnosis and know that you matter as a person.

Staff: To feel that your communication and care is valued and important and that your work and contribution matters.

This has been modified from Nolan et al 2004⁸, and Nolan et al 2001, P 175.⁹