



The
Bernie Banton Foundation

QUESTIONS

to answer regarding

SURGERY

Support – Inform – Advocate – Empower

Questions To Find Answers To When Discussing Radical Surgery

Please note: When discussing surgery it is important the surgeon is giving information relevant to the patient being discussed. When you are doing research about surgery treatments, and surgeons are talking about comparable patients, comparisons should be made by evaluating patients:

- With the same type of mesothelioma;
- Being the same gender and a similar age **when** the surgery was performed; and
- Have similar history of general health and well being prior to the operation having been performed.

About The Questions

The questions have been put together, not to solicit guarantees from a surgeon (something they can't give), but for you to be able ask questions that will allow you to come to a conclusion that you and your loved ones are comfortable with, and importantly will have no regrets about.

Surgeon Name:

Surgeon Qualifications:

Type of Surgery:

Hospital where surgery will be performed:

Address:

Hospital where follow up treatment will be performed (chemotherapy/radiotherapy?):

Name:

Address:

Treatment:

Explanation of the Operation

- **Has an overview of what the operation is all about, in easily understandable layperson terminology, been given or obtained?**

Yes No

Explanation:

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.....

.....

Patient Disease Treatment History

- **What treatment history (if any) disqualifies a patient from undertaking the operation?**

Answer:

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Testing Needed To See If A Patient Qualifies For Operation

- **What testing does the surgeon require the patient to undertake to be able to make a fully informed decision on the suitability of the patient for the operation, and importantly that the operation can physically be carried out?**

Answer:

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Preoperative Chemotherapy

- **Is a course of chemotherapy treatment required before the operation?**

Yes No

If yes, what does it entail?

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Qualification of the Surgeon's Experience

- **How many operations, of the type being discussed, has the surgeon done on comparable patients?**

[] operations performed

- **Is the surgeon part of an applicable Multi Disciplinary Team (MDT)?** Yes No

(A MDT is a team of specialists encompassing the full spectrum of treatment and care possibilities for a particular disease.)

- If yes, is the MDT based at the hospital where the surgery will be carried out?

Yes No

- If no, where is the MDT based?

- **Does the surgeon know of any people who will be contactable by the patient, who are:**

- Comparable **surviving** patients who **have had successful results** (patients who are enjoying quality of life after the operation)?

Yes No

If yes, how long have they survived after the operation?

[] x 1 year [] x 2 years [] x 3 years [] x 5 years [] over 5 years

- Comparable surviving patients who have **not had successful results** (patients who are survivors but have never regained a quality of life)?

Yes No

- Bereaved Carers of comparable patients who lived **less than 2 years** after the operation?

Yes No

- Bereaved Carers of comparable patients who lived **more than 2 years** after the operation?

Yes No

Notes:

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Survival Time Estimates and Studies

Points to consider: All treatment options are considered as being **palliative**. When it comes to asbestos disease, **nobody** has a ‘crystal ball’ that can forecast how any individual will respond to standard ‘non-radical’ surgical and therapy treatment options, or how long that response will last. Similarly, the same can be said of ‘radical (aggressive)’ surgical treatment options, whether combined with therapy options or not.

- **How long does the surgeon estimate the patient will survive with ‘quality of life’ utilising standard ‘non-radical’ surgical and/or therapy treatment options, or viable alternative therapy treatment options?**

[] Months [] Years

On what basis is this estimate reached?

.....
.....
.....

- **Is the surgeon prepared to give an estimate of the expected increase of survival time with ‘quality of life’, the operation will give, over and above standard ‘non-radical’ surgery/treatments options?**

Yes No

- If yes, how many months or years after the operation and associated recuperation time does the surgeon estimate?

[] months [] years

On what basis is this estimate reached?

.....
.....
.....

- **Does the surgeon know of, or can point to any peer-reviewed trial or study results indicating how long the proposed radical surgery/treatment regime gives, and prolongs ‘quality of life’ over and above standard surgery/treatment?**

Yes No

If yes, please note study titles(s) and reference details:

.....
.....
.....
.....

Survival Rates After The Operation

- **What % of comparable patients do not live through the operation, or only live up to 12 months afterwards?**

[] %

- **What % of comparable patients survive, after the initial operation and treatment regime, without needing follow up operations or treatments for:**

2 years []% | 3 years []% | 5 years []% | More than 5 years []%

- **What is the average post operation survival times of comparable patients, who have had the operation?**

[] months [] years

Notes:

.....

The Operation

- **Preoperative time needed:** [] hours on (please tick) Day before [] Other []

Other details:

.....

- **How long is the operation expected to take?** [] hours

- **What could stop the operation being completed once it has started?**

Details:

.....

Recovery Time After The Operation

- **What amount of time should a patient expect to be in hospital after the operation?**

[] days [] weeks [] months

- **Is it expected the patient will get back to 'prior to operation' wellbeing after leaving the hospital?**

Yes No

- **If yes, how long is it expected to take?** [] weeks [] months

If no, what should be expected?

.....

Permanent Impairment

- Are there known permanent impairments/disabilities, etc. that will result from the operation?

Yes No

If yes, what are they?

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Operation Side Effects

- What are the typical side effects experienced by comparable patients?

Answer:

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.....

- What impact are these side effects likely to have on quality of life?

Answer:

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.....

- How long does the surgeon expect the side effects to last?

[] weeks [] months [] years [] ongoing

Notes:

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.....

- If the patient lives remotely from the surgeon (in a country region or interstate), will side effects (including pain control) be able to be managed locally?

Yes No

If yes, please detail:

.....

.....

.....

Postoperative Radiotherapy

• **Will radiotherapy be necessary after the operation?** Yes No

• **If yes:**

○ Where will it need to take place?
.....

○ How long after the operation will it need to commence?

[] immediately [] days [] weeks [] months

○ How long will each treatment take? [] minutes [] hours

○ How many treatments will be necessary? [] treatments

○ At what interval between treatments? [] days [] weeks [] months

○ Will the treatment require hospitalisation? Yes No

If yes, for how long? [] overnight [] days [] weeks

• **What are the known side effects of the radiotherapy?**

Details:
.....
.....
.....

• **How long are they likely to last?** [] days [] weeks [] months [] permanent

Postoperative Chemotherapy

• **Will chemotherapy be necessary after the operation and/or follow up radiotherapy?**

Yes No

If yes, note details:
.....
.....

Supportive Care After Leaving Hospital - General Questions

- **Who will be responsible for organising and overseeing:**

- Postoperative treatment (chemotherapy, radiotherapy, etc.)?

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.....

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- After surgery/postoperative rehabilitation?

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- **Will the surgeon cease taking responsibility for the patient's overall and holistic wellbeing?**

Yes No

If yes, please qualify the following:

- At what point or stage does this occur?

.....

.....

.....

- Who will then be responsible for managing the patient's future wellbeing (such as pain control, etc.) and any necessary treatment that may become necessary?

.....

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.....

- **If the patient lives in the country, or interstate, does the surgeon have any specialists conversant with the operation and aftercare, close to the patient's hometown/area, who he/she can liaise with to oversee the patient's recovery period and future wellbeing?**

Yes No

If yes, please detail:

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.....

.....

Supportive Care After Leaving Hospital – Palliative Care

- **Will the patient need to be registered with a Palliative Care network?** Yes No

If yes, will the surgeon organise this? Yes No

If no, who will, or need to?

Notes:

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Supportive Care After Leaving Hospital – Rehabilitation

- **Is it expected the patient will need to have rehabilitation?** Yes No

If yes, for approximately how long? [] days [] weeks [] months

- **Will this need to be at a rehabilitation centre?** Yes No

If yes, will it be live in or daily sessions, or a combination of both?

(Please tick box) Live In [] Day Sessions [] Combination of both []

- **Estimated rehabilitation timeline details:**

Live in at rehabilitation centre: [] days [] weeks [] months

Day sessions at rehabilitation centre: [] days [] weeks [] months

Rehabilitation sessions at home: [] days [] weeks [] months

Postoperative Care After Leaving Hospital – At Home

- **Will the patient's home need to be assessed by an Occupational Therapist (O/T)?** Yes No

If yes, will the surgeon organise this? Yes No

If no, who will?

.....

- **After being discharged, is it expected the patient will be bedridden?** Yes No

If yes, for approximately how long? [] days [] weeks [] months

- **If no, is it expected the patient will be able to:**

- Toilet and shower (or wash) without assistance? Yes No

If no, for approximately how long? [] days [] weeks [] months

- Negotiate stairs to upper level rooms? Yes No

If no, for approximately how long? [] days [] weeks [] months

- **Is it expected the patient's carer will be able to administer medications and pain control drugs as required?**

Yes No

- **Is it expected the patient will need specialised 'in home' nursing care assistance?**

Yes No

If yes, at what frequency? (please tick box) Daily [] Weekly [] At Call []

For how long (approximately)? [] days [] weeks [] months

- **Is it expected the patient will need specialised aids or equipment? Such as a:**

- Wheelchair Yes No
- Shower stool Yes No
- Hospital-type bed Yes No
- Hospital-type airbed overlay Yes No
- Any other aid that may assist a patient to maintain dignity and quality of life

Other:

- **Who will be the patient's primary carer?**

Has she or he been fully informed and consulted as to whether he or she feel they will be able to cope with caring for the patient at home?

Yes No

IN CONSIDERATION

It is worthwhile considering at length the answers you find or receive to these questions, and also remembering that **no** surgeon or specialist has a 'crystal ball'.

When analysing figures in studies comparing standard non-aggressive surgery and therapy based treatments outcomes, against 'aggressive' surgery outcomes, be mindful of the fact normally only patients who have gone well on standard treatment and considered 'fit' with a general 'good wellbeing' are accepted to have aggressive surgery operations.

Therefore it could reasonably be said these patients may have achieved the same, or extra longevity and quality of life by purely having continued their existing treatment regime. Really nobody can know that, it is why your decision should be made on a fully informed and considered basis.

We recommend you do not sign anything on the spot, or be unduly hastened into having the surgery - take time to consider and discuss the options, and possible ramifications, with those close to you. It is sometimes also helpful to speak to those who have been on a similar journey (those who have had a good journey, as well as those who haven't). If the surgeon has not been able to tee this up, we may be able to do so.

'Please also discuss your thoughts, findings and any questions you may have with the MARS Support Co-ordinator before making a decision'

If in doubt at all about whether to have surgery or not, please seek an independent expert second opinion before making a decision. **It is your life journey and your decision to make!**

We hope you have found this document helpful in allowing you to become more fully informed, and wish for you the best possible journey, with quality of life and no regrets about the decisions you make during the journey.

With the warmest regards and blessings,

Rod Smith

Rod Smith
Support Co-ordinator

MARS

MESOTHELIOMA
AND
ASBESTOS RELATED
SUPPORT



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