Mesothelioma UK carried out a National Patient Experience Survey in 2012 and the results showed an alarming disparity between the treatment and healthcare services provided to people diagnosed with mesothelioma within the UK.

At this years Mesothelioma National Patient and Carer Day, Liz Darlingson, Consultant Specialist Lung Cancer Nurse and founder of Mesothelioma UK provides her 10 Top Tips for improving the lives of those living with mesothelioma:

1. ***Knowledge is power:***

Be aware of what treatments and trials are available and the health and support services you are entitled to receive. Did you know there are set Government guidelines and standards which Health Authorities must provide to people diagnosed with mesothelioma?

These guidelines and other vital information about your illness are available from the following internet sources:

www.mesothelioma.uk.com
www.cancerresearchuk.org
www.macmillian.org.uk

Or simply call Mesothelioma UK's free helpline on 0800 1692409 where they have specially trained people on hand to provide help and assistance.

2. ***Develop your own team and be the boss:***

- Identify your key worker, this is usually your Lung Cancer Nurse unless you are fortunate to be in an area with a designated Mesothelioma Specialist Nurse.
- Identify a Lead Consultant whom you have a good relationship with.
- Make contact with your GP and let them know they will be managing your problems on a day to day basis.
- Most importantly identify a "buddy" who will be able to speak up for you and help coordinate your care when you do not have the strength. This is usually your partner.

3. ***Communication is vital:***

- Never presume communication between your health and social care providers has happened.
- Keep a diary of your health, treatment, appointments, symptoms and any medication you are taking. When someone new becomes involved on your care you will be the only one that can provide a holistic account of your illness and treatment.
- Don't wait for your routine follow up appointments to discuss your concerns. Identify and use an accessible source such as your Specialist Nurse or your treating Consultant's secretary to arrange an early time to discuss your concerns.
- Most importantly tell your doctor and nurse what you do or do not want to hear. It is your illness and your journey and they are just there to help and support you along the way.

4.***Access expertise:***

- Be proactive about your illness. If you have not seen your Consultant for a while don't be afraid to voice that you want to see the Consultant when you arrive at your clinic appointment.
- It is not your legal right to a second medical opinion but it has never been known to be refused in a mesothelioma patient. But if you are seeing a new specialist, make sure all your x-rays and notes are passed to them before your appointment.

- If you would like someone else to attend your appointments to help you decide on treatments, ask to have your advocate with you, this is likely to be your allocated "Buddy".
- Keep abreast of what clinical trials are available and how to take part, by looking online at www.mesothelioma.uk.com or calling the free hotline 0800 1692409.

5. ***Talk and network:***

- Access local and national support groups.
- Engage in social media.
- There are a lot of people out there who are also suffering with mesothelioma and understand what you are going through.

6. ***Exercise is crucial:***

- Even if you are wheelchair bound you need to "move it or loose it"!
- Guard your mobility with your life.

7. ***Accept that mesothelioma changes your life and be prepared to adapt to change with it:***

- Look at new ways of doing things.

8. ***Hope is vital:***

- Remain positive and stay away from people or things that make you feel down.

9. ***Look after your emotional self:***

- How you feel emotionally is really important, some say it can help you cope with your illness and your treatment.

10. ***LIVE:***

- Make mesothelioma a part of your life, don't let it BE your life. If you want to do something like travel, do it! Of course it will take a lot more planning but there is a team of people at Mesothelioma UK dedicated to help you plan and do the things you still want to do.