



MDT - from the patients' perspective

**Comments and observations from cholangiocarcinoma
patients and their families**

**ESSO-BASO Cancer MDT Course
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INTRODUCTION

Prior to speaking on the subject, “MDT – The Patients’ Perspective” at the ESSO-BASO* Cancer MDT Course on 01 November 2014, AMMF’s Helen Morement used the charity’s Facebook page to invite supporters to supply answers, comments and thoughts, either openly on the public site or privately by email, on the following series of questions:

- 1. If you, or someone you are close to, has been diagnosed with cholangiocarcinoma, were you/they told that your/their treatment would be discussed at an MDT meeting?*
- 2. If you were told about an MDT meeting, did you know what this meant and did you understand what would be happening?*
- 3. Did you have an opportunity to ask questions about this, and were they fully answered to your satisfaction?*
- 4. How were the decisions on treatment options reported back to you?*
- 5. Did you have an opportunity to ask questions about this?*

The majority of respondents, whether commenting openly on Facebook or via email, agreed to their responses and names being shared. Their information provided the detail for the presentation, and the responses are shown in full on the following pages.

This document was prepared and circulated as a handout to all attendees at the ESSO-BASO Cancer MDT Course.

* ESSO - European Society of Surgical Oncology
BASO - The Association for Cancer Surgery

Kellie: We were told on the day that the diagnosis was given to us that my Dad's case would be discussed by a MDT at the Christie and that numerous professionals attend these meetings.

The clinical nurse at Royal Bolton hospital said she had rushed through our appointment at which the doctor told us it was cancer so my Dad's case could be discussed at that Wednesday's meeting otherwise we'd have to wait until the following Wednesday for his case to be discussed.

We weren't told we could ask questions we didn't get much feedback apart from being told that my dad wasn't able to be operated on but that chemotherapy was an option to control not cure it. That's it really and I suppose I would have liked the chance to speak to some of the people at the meeting and maybe ask further questions, but at least we were told this much.

Of course I completely understand that we aren't allowed to attend the meetings, nothing would ever get decided on! And yes, I agree that more could be done to make us feel fully involved however like I say I appreciate that with the number of cancer patients ever increasing then there has to be a limit to that involvement.

I suppose I'm trying to understand from the medical profession's point of view as well but that's not my problem to worry about when I have enough to deal with, and I've never felt I could just pick up the phone or email someone about this because no one has told us this is something we can do. If we had access to a patient advocate that could make this whole traumatic experience a little easier.

Malcolm: I recall being told after diagnosis that my case was to be discussed at a meeting in another hospital and that this was attended by a range of medical specialists from a wide area.

MDTs exist in other professional areas and I had attended many over the years. Some of these events had been very positive and some less so - dependent on those attending and particularly the 'chair/lead professional'. Decisions taken by committee can sometimes involve compromise.

I do remember thinking I hope the key individuals are all actually there. I also remember that this was an unusual approach and that this thickened the fog of firstly a cancer diagnosis and secondly one that was complex.

The effect on the patient of the apparent delay in agreeing a way forward even for a day or a weekend should never be underestimated. This sends a very mixed message.

The lack of the usual pathway of one individual surgeon explaining what procedure they intended to carry out was unsettling.

Would literature on what an MDT consisted of help? I'm not sure for me but for those around me yes. My outcome was resection and thus not typical here.

Gail: We have been told on numerous occasions about my husband's case being discussed at the MDT meetings, which have mainly been reported back to us via the oncologist either by telephone or at our next clinic appointment.

Marie: As a nurse myself I fully understood what an MDT was, what would be discussed etc, but it was frustrating that I had to constantly explain the medical terminology to my mom and the rest of the family. I often felt medical and nursing staff spoke to me rather than my mom who was the patient.

The decision on treatment options were discussed and we were given time to ask questions, in fact the Dr explained things clearly and used appropriate sketches to explain why and allowed my mom to take them home. When mom had her chemo regime explained it was also written down for her.

Mom's case was discussed in numerous MDT's and we were always aware when these were taking place and why, the outcomes were discussed and on more than one occasion the Dr also rang me (at my mom's request) to inform me.

Having to wait for an MDT meeting can be frustrating but it is necessary to have all the specialists etc together.

Lucie: My mum had her case dealt with by an MDT and although we were grateful that such expertise was 'on the team' I recall feeling immense frustration that their weekly - or even bi weekly - meetings were so rigidly timed. For example, there could be a MDT meeting on a Wednesday afternoon, but if my mum had a scan on a Thursday morning she could have to wait up to 2 weeks for the results to be discussed.

I recall several calls to the hospital begging staff to run scan results down to the appropriate secretary so that they could be included in that afternoons discussion. For all cancers - and specifically nasty time critical cancers like cholangiocarcinoma - I wondered why there wasn't a better solution to this. Two weeks could mean all the difference. Technology has surely evolved?

If I was going to add another point about the MDT it would be nice to understand how and why decisions have been reached - and to receive feedback. I'm happy to elaborate if necessary.

Margaret: At the time of Derick's first op, there was no mention of MDT because it was originally thought he had pancreatitis but, two weeks later, when we got the cholangiocarcinoma diagnosis as a result of the histology report, we were told that there would be an MDT meeting the next Tuesday, a weekly event, involving, among others, the liver surgeon, who had performed the op, and the oncologist and the next steps would be discussed.

As Derick was still in high dependency due to post op MRSA, the outcome of the meeting was discussed with us in the ward with plenty chance to ask questions.

A year later when the cancer had spread to the duodenum, it was very different. There was an MDT meeting but he was in a different ward /dept and we had great difficulty getting any information. Indeed the impression we got was that the professionals couldn't agree on next steps. Perhaps the decision was more difficult to make, I don't know, but it was upsetting as we felt we were being kept in the dark.

Derick would never make a fuss but I did the fuss bit for both of us, desperate for information. Two extreme opposite experiences, and I know which we preferred. It was so much better first time round to feel involved in the post MDT deliberations and have the opportunity to ask questions

Andrea: We were told by Russells Hall hospital that the QE had discussed and diagnosed Dad's cancer at a MDT, they then transferred Dad to the QE hospital for his stent procedure. Russells Hall Hospital had told us Dad had a few months to live but the QE offered Chemo and disagreed with the 2 months to live! Mixed message from the MDT??

Six months later Dad's case was discussed again at a MDT and it was decided nothing could be done, this news was broken to Dad by the Macmillan nurse and he never saw the consultant again.

Both times we were told after the MDTs and didn't have a chance to put our questions forward. I often had to try and phone or even email them to ask questions and get answers.

Sandie: I knew what an MDT was, but it has never been mentioned to me.

1. My first experience was in France.
2. My second experience was at Kings Mill Hospital in Mansfield. Once it had been discovered that I had tumour recurrence, my oncologist simply told me that if I thought I had a tough time last time, it was nothing compared to what will happen. She told me I had 18-21 months to live (this was in July 2013), then told me to have a cup of coffee before driving the 45 minute journey home. I was on my own. There was no discussion at all regarding any treatment.
3. My third experience was with Prof Valle and members of his team in Manchester who were excellent in explaining what and when was going to happen. He did not mention an MDT but I certainly got the impression that my case had been discussed with others. He explained that I was to have Gemcitabine/Cisplatin and referred me to Nottingham City Hospital for treatment.

4. My fourth experience was at Nottingham. My oncologist explained every part of my treatment and, upon asking, explained why radiotherapy and surgery were not options in my case. I was happy with the decisions made and again, felt my case had been discussed although there was never a mention of an MDT.

My only comment is that although I appreciate it would not be appropriate for a patient to attend an MDT, I think it would be helpful for members of the MDT to meet the patient for them to assess strength of character, attitude etc which could have an impact on decisions made. It could also be of benefit to the patient to gain confidence in the decision making process.

Beryl: I can honestly say I was told nothing. I went to see a liver consultant at the hospital, and I was taken into a room full of people - I had no idea who they were. A consultant introduced himself and told me I needed a major operation as I had a tumour on my liver that needed to be removed. He said you have us baffled, there's no cancer showing in your body, but you need a major operation. MDT was never mentioned. I can recall being so confused that I cancelled the operation because of lack of knowledge.

It was only when I was appointed a new consultant that I was invited to his clinic to ask questions and fully discuss my options and be told exactly what to expect,

Clare: We were told very early on my sister's case would be discussed with an MDT. I'm not sure that the word MDT was used but she knew that every Friday afternoon a meeting was held with surgeons, oncologists, etc. I knew what it was as nurse, so could explain it.

Whenever a decision was being made at the MDT, my sister knew she was being discussed at the meeting and was told by her surgeon that he would ring her after. This was always after 5pm on a Friday. He always phoned and I have to say the news she was given was always extremely hard to hear. It had to be done by phone because of the distance involved and the rapidity of decisions being made and plans put in place. She was always allowed to ask questions but often more cropped up after the phone call and she had to wait until Monday to contact a professional. That is no-one's fault and not a criticism but maybe a Friday 3pm MDT meeting is not the ideal time if you are delivering difficult news.

Stewart: I had a MDT before my surgery and took the advice that any delay would cause further problems down the recovery road. Diagnosis to Operation (Whipple) two weeks. I believe that saved my life.....

And a comment from the US:

Leslie: My husband was diagnosed with ICC in January of 2013. We live in Syracuse, NY. He was scheduled for a biopsy but we wanted a second opinion at a major center so we went to the Cleveland Clinic. After multiple tests and a biopsy we were told that results would be presented at a "Tumor Board" which was an MDT. We were only told their decision which was to have a resection removing 60% of his liver and his gallbladder. There was no other discussion re the reason. He is considered Stage II. Clear margins and nodes with a small vascular invasion. No other treatment. He had scans every 3 months for a year and now every 6 months. Surgeon and care were great! He is considered in remission.

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