**Celia Kitzinger** @KitzingerCelia

27 Jan • 18 tweets • KitzingerCelia/status/1354480445757468678

Today's hearing was about RS who is 30. Four months ago he was diagnosed with testicular cancer. His left testes was removed, but the cancer has spread. Without treatment he'll die within a year. With usual t'ment, a 95% chance of cure. Trust referred RS to palliative care only.

His mother advocated for him. Best interests meeting was convened. Agreed usual treatment ("BEP" - Bleomycin, Etoposide, Platinum (Cisplatin) chemotherapy) is not suitable for RS. He'd need to be under GA for 70+ hrs due to inability to tolerate clinical intervention.

RS has Fragile X syndrome, atypical severe autism, learning disability + limited communication. But described by his consultant oncologist as "a fit lad with no physical difficulties".

Given the very good prognosis with treatment, RS's age, his "zest for life" and the presumption in favour of life, the option of no active treatment is manifestly NOT in RS's best interests.

The Trust then came up with a treatment plan.

The Trust's plan involves 4 cycles of modified chemotherapy - designed to avoid too much GA and to allow administration of medication in tablet form at home

If metastatic lymph nodes were still present after this, then surgery would be offered (RPLND).


**Retroperitoneal lymph node dissection (RPLND) - Macmillan Cancer S…**
Men with testicular cancer may need surgery called, retroperitoneal lymph node dissection (RPLND) to remove the lymph nodes at the back of the tummy (abdomen).

https://www.macmillan.org.uk/cancer-information-and-support/treatments-and-drugs/rp…

The Trust also obtained a second opinion from Prof Huddart.

His recommendations were different.

In court he said, surgery first with "adjuvant chemotherapy" after.

Also keyhole 'robotic' surgery (which isn't available at the treating hospital).

https://www.royalmarsden.nhs.uk/our-consultants-units-and-wards/consultant-directory/professor-robert-huddart

The case came to court because RS's mother - now his litigation friend - did not accept Trust's treatment plan + wanted more exploration of the options, including the plan from Prof Huddart - which Trust is "not willing or able to provide". Only t'mens option was Trust's option.

RS was represented by Parishil Patel @parishil100 @39EssexChambers (instructed by @MrsArcticride via his mum as litigation friend)

Trust was represented by Emma Sutton @sutton_es
@serjeantsinn

The judge was Mrs Justice Lieven

#NotSecretCourt

Three clinicians in court: oncologist + critical care drs from treating hospital + Prof Huddard.

Some very technical medical discussion.

Mrs Justice Lieven is brisk, efficient, straight-talking and intervened to ask questions at exactly the points I got lost in the evidence!

Best interests discussion covered comparative risks + benefits associated with surgery now vs. (possibly) later, prolonged sedation, different meds, transfer to hospital 100s miles from home, likelihood of success with oral meds (hidden in yoghurt) vs intramuscular injections...

Trust doctors expressed huge concerns about Prof Huddart's suggestion of Bleomycin (due to risks with GA oxygen). "We couldn't justify to ourselves subjecting P to this under any circumstances".

Trust does not use Bleomycin with other patients with RB's clinical presentation.

There was an extended lunch break so that counsel for RB could discuss the new evidence in court (some of which departed from the evidence provided in advance) with RB's mother.

After lunch break, Parishil Patel @parishil100 said his instructions were that RB's mother (+ LF) now agreed to the care plan proposed by the Trust.

On Bleomycin, "they're not prepared to offer it so it doesn't matter what we think - it's not an option"

Lieven J: "It matters for [Mum] to hear that the reason Bleomycin is not being offered is not doctors being difficult or obstructive or risk-averse, let alone money considerations. It's that there's more harm attached too giving it than not."

Mum nods.

"Drs are not giving Bleomycin to patients who have the same prognostic indications as RB + there's nothing in his clinical picture that indicates he should be treated differently. That was only made clear this morning"

Also mother is confident that oral administration of Etoposide will be possible, so IV infusion recommended by Prof Huddart (+ not by Trust) won't be necessary.

But is reassured that if it becomes necessary + there's no other option Trust will go down IV route.

So Trust's treatment plan is agreed + Lieven J mades order under s 16 MCA that it's in RB's best interests. She's "very glad [Mum] has come to the same conclusion".

RB to hospital 5pm today - treatment starts tomorrow.

An excellent outcome.

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Correction: I'm informed that it was not "as a consequence of RB's mother advocating for him" that the Trust changed a decision they had made for palliative care. As BEP chemotherapy was not clinically appropriate they were looking for a modified plan.

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