

CARE AFTER OVARIAN OR TESTICULAR TISSUE PRESERVATION: A LONG TIME OF NOTHING

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INTRODUCTION:

Childhood cancer treatment can cause harm to a child's ovaries or testicles and cause infertility. Ovarian or testicular tissue can be preserved before treatment, but it is not fully known how effective preservation is.

Approximately 800 children undergo tissue preservation each year in the United Kingdom (UK), but there is no standard care pathway for follow-up. Ensuring appropriate long-term care of this emerging population is crucial.

OBJECTIVES:

(1) To learn about the needs and experiences of young cancer patients, their caregivers, and healthcare professionals related to ovarian or testicular tissue storage and care.

(2) To inform standardisation of NHS care for young people who store ovarian or testicular tissue before cancer treatment to preserve their future fertility.

METHODOLOGY:

Seven individual interviews with young people, parents and healthcare professionals took place. Interviews were informal and conducted via an online meeting platform or telephone call.

Participants included parents of children who had stored tissue, a young adult with fertility issues arising from childhood cancer treatment, and four clinicians from the leading NHS centres in the UK.

WE ASKED:

- Can you tell me about any follow-up care you/your child has had after you had stored tissue? (patients/parents)
- Can you tell me about the follow-up care you provide to patients after they have stored tissue? (clinicians)

We've never really explained to [our son] what's happened to his fertility. And now he's 11 [...] I mean, we've just done it without him knowing and he still doesn't know his fertility has been affected [...] it's just something we don't know how to broach or discuss with him. - Parent

The oncologist was amazing, but tissue preservation was not the priority at the time. Since then, there has been nothing instigated or talked about in-depth about the stored tissue [...] I still feel like if I lose this bit of paper, I've only got that. - Parent

It's going to be our responsibility for 20 years, and I don't know anything more than that. I don't know how to bring it up or talk with [my child] about it, how do I find out? - Parent

My mum was really worried and upset. There wasn't any support like counselling or anything like that; it was just get on with it yourself and see you next year. - Young Adult Survivor

Our peers have a normal life and can't understand; they can't imagine it. - Young Adult Survivor

It was never discussed until I brought it up [...] I think it should be brought up sooner, e.g., as teenagers, sooner rather than later [...] I had to push hard to talk to anyone about my fertility. - Young Adult Survivor

Young people don't know the information, they don't always know they have preserved fertility [tissue]. It's such a confusing and difficult thing; they want information sooner, they want to know about the future. - Clinician

There is nothing at all to help them five years or more post-treatment. At the moment, we provide reassurance, talk to parents, and then send them on to the tissue storage centre. The preservation happened, but they know nothing after that. - Clinician

Parents are worried about talking about it and telling their child, so they avoid the subject. [...] most haven't started the conversation yet, and some need a lot of help. Some will never start that conversation. - Clinician

Teenagers require information about their situation because, to them, fertility tissue preservation was seen as a backup plan. - Clinician

“THERE WASN'T ANY SUPPORT LIKE COUNSELLING OR ANYTHING LIKE THAT; IT WAS JUST GET ON WITH IT YOURSELF”

KEY ISSUES :

Young people, parents and healthcare professionals expressed the importance of support for:

- Knowing how and when to talk about the topic
- Managing emotional and psychosocial needs during follow up
- Managing the negative emotional impact of uncertainty

CONCLUSIONS:

Informal interviews underscore the need for personalised follow-up care encompassing informational, psychological, and support aspects.

The concerns raised by young people, parents and healthcare professionals emphasise the urgency for research to address gaps in follow-up care.

Future interventions must prioritise understanding and meeting survivorship needs of individuals who have undergone ovarian or testicular fertility preservation treatments, ensuring comprehensive care, accurate information, and appropriate support.



Further information can be found via our website <https://ukfertilityregister.org.uk/>

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