

# The DIGNISPACE Study

## Co-designing a digital meaning-making and legacy leaving intervention for young people with life-limiting conditions

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### Background

Dignity Therapy (DT) is a psycho-therapeutic end-of-life intervention supporting life review, meaning making and legacy leaving.<sup>1</sup> DT is well received by adult patients and family members, with research identifying improvements in measures of well-being.<sup>2</sup> Few studies have included young people (YP) (18-24yrs) with life-limiting conditions (LLC)<sup>3</sup>.

Our literature review<sup>3</sup> and consultation work with service users, family members, carers and health care professionals (HCP)<sup>4</sup> suggested a need to develop a **digital DT based intervention** for YA/LLC. In doing so we also determined a model of Dignity in YP/LLC.

*We recognised how a DT based intervention could enhance the work healthcare professionals do with YA/LLC and their families: memory making, legacy leaving, end-of-life care & bereavement*

### Aim:

To co-design a digital DT based intervention, called DIGNISPACE, for YP/LLC.

### Background

#### Examples of Dignity Therapy Questions<sup>1</sup>

*“Tell me a little about your life history, particularly the parts that you either remember most, or think are the most important. When did you feel most alive?”*

*“Are there specific things that you would want your family to know about you & are there particular things you would want them to remember?”*

*“What do you feel most proud of?”*

*“Are there words or perhaps even instructions you would like to offer your family to help prepare them for the future?”*

### Methods

- ❖ Qualitative methods included focus groups with health professionals (n=23), semi-structured interviews with YP/LLC (n=13) and family carers (n=12).
- ❖ Data were analysed using framework approach. Participants were recruited from hospices in the North of England.
- ❖ An advisory group of YP/LLC and their carers supported the study and content of DIGNISPACE.

‘... it's just giving people the permission to talk about it... I think this is a brilliant idea’ **HCP**

‘People want to make sense of their lives or kind of to gather things together, or they want to revisit things... we've seen that recently with families here. Going back to places that have been meaningful, you know saying goodbye’ **HCP**

‘....young people are protective of their parents...working nights ...staying up late they would want to talk about these things, but would say I don't want you to tell my parents, about this’ **HCP**

‘I love the idea of a little time capsule. I think that’s awesome. It’s easy to access; I think little Polaroid style pictures or little bits of writing....It could even go swoosh (when you open it)’ **YA/LLC**

‘If an individual feels confident enough to unlock the question in the first place, I think something beneficial is happening already. Obviously, the option of help and support would be there... I think that would be something the parents and the family would go, my god, they’ve done that all themselves, I think it would be incredible for that to be just purely down to that individual’ **YA/LLC**

### Participant Perceptions

‘....maybe something like DIGNITAL could help to start having the wider conversations and for others to maybe accept it’ **YA/LLC**

### Results

Three overarching themes were derived:

- 1) Intervention purpose including amendments to the DT question protocol;
- 2) App components, content and delivery;
- 3) Networks and support systems.

Findings informed a model of dignity in YP/LLC and DIGNISPACE.

DIGNISPACE is implemented as a React Native app accessible via Android and Apple devices, and web browsers.

- ❖ DIGNISPACE (name suggested by advisory group and agreed by participants), considers what dignity means to YP/LLC and meets some of the psycho-spiritual needs they face with medical uncertainty and a shortened life prognosis. DIGNISPACE content, when shared, will provide comfort for others in bereavement.
- ❖ Built around a bubble concept, users are supported to leave different content for different people, drawing on multimedia.
- ❖ DIGNISPACE will support YP/LLC from varied ethnic and cultural backgrounds, with diverse communication abilities and different levels of mental capacity<sup>5</sup>.

- ❖ **DIGNISPACE** is a co-created psycho-therapeutic digital intervention that supports the needs of YP/LLC.
- ❖ It can be used alone, or with HCP, friends, and family.
- ❖ DIGNISPACE includes tenets of the model of dignity for YP/LLC in its content and delivery<sup>5</sup>.
- ❖ Further research is required to explore feasibility.

#### Impact

- ❖ We have created a new model of dignity for YP/LLC to shape future interventions.
- ❖ YP/LLC and carers want to use DIGNISPACE
- ❖ DIGNISPACE helps health care professionals to work more sensitively with young people and families.
- ❖ The proof-of-concept could be developed to support other populations facing end-of-life.

### Conclusions

#### References

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