

## From research to practice: improving early-stage engagement with palliative care for patients and families living with mesothelioma

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**Objectives:** Mesothelioma is a condition without cure with a high symptom burden, and both patients and families live with uncertainty. Palliative care can ease the burden of both patients and families through a holistic approach addressing physical, psychological and spiritual needs.

The Mesothelioma UK Research Centre (MURC) undertook research to:

- identify the palliative care needs of patients and their families, and any gaps in care, and to
- explore the palliative care role of charity-funded Mesothelioma Clinical Nurse Specialists (MCNSs) within the UK.

Key findings from the research were taken forward within a collaborative approach to develop tools with a goal of improving early-stage palliative care uptake and support for mesothelioma patients and their families.

**Methods:** The mixed methods study<sup>1</sup> drew evidence from both patient and MCN perspectives utilising: a literature review of current evidence; secondary analysis of patient survey data (n=510); and a cross-sectional survey and focus groups with MCNSs.

Data analysis identified gaps in access to palliative care that could be addressed via evidence-based tools.

A co-production approach brought together a creative design company with patients/families, researchers, clinicians, and the charity Mesothelioma UK. The collaboration produced an animation and infographic, drawing together research findings and lived experiences.

**Results:** The research found that patients (and their families) have palliative care needs across the disease trajectory. MCNSs are highly skilled and play a key role in both the provision and coordination of care. Nurses perceived that palliative care works best when engaged with at an early stage, so that patient and family can make choices in advance of need.

Key gaps in care were identified. Patients and families can be hesitant to engage with palliative care due to misconceptions and negative associations. In addition, referrals to specialist palliative care are inconsistent, preventing timely access.

To address these gaps, two tools were developed to encourage early-stage engagement with palliative care, and facilitate smoother referral routes: -

1. **A short animation**, aimed at patients/families which explains the role of palliative care in mesothelioma, addresses misconceptions, and encourages engagement. The animation is freely accessible via the Mesothelioma UK website and can be used as a tool for professionals to open conversations about palliative care with patients/families, or as a resource patients/families can access and view themselves (figure 1).



Figure 1: Animation

2. **An infographic**, aimed at healthcare professionals (particularly primary care teams) to provide key information about mesothelioma and palliative care needs in order to foster well-coordinated care. The one-page infographic provides background information and signposts to sources of help at Mesothelioma UK (figure 2)

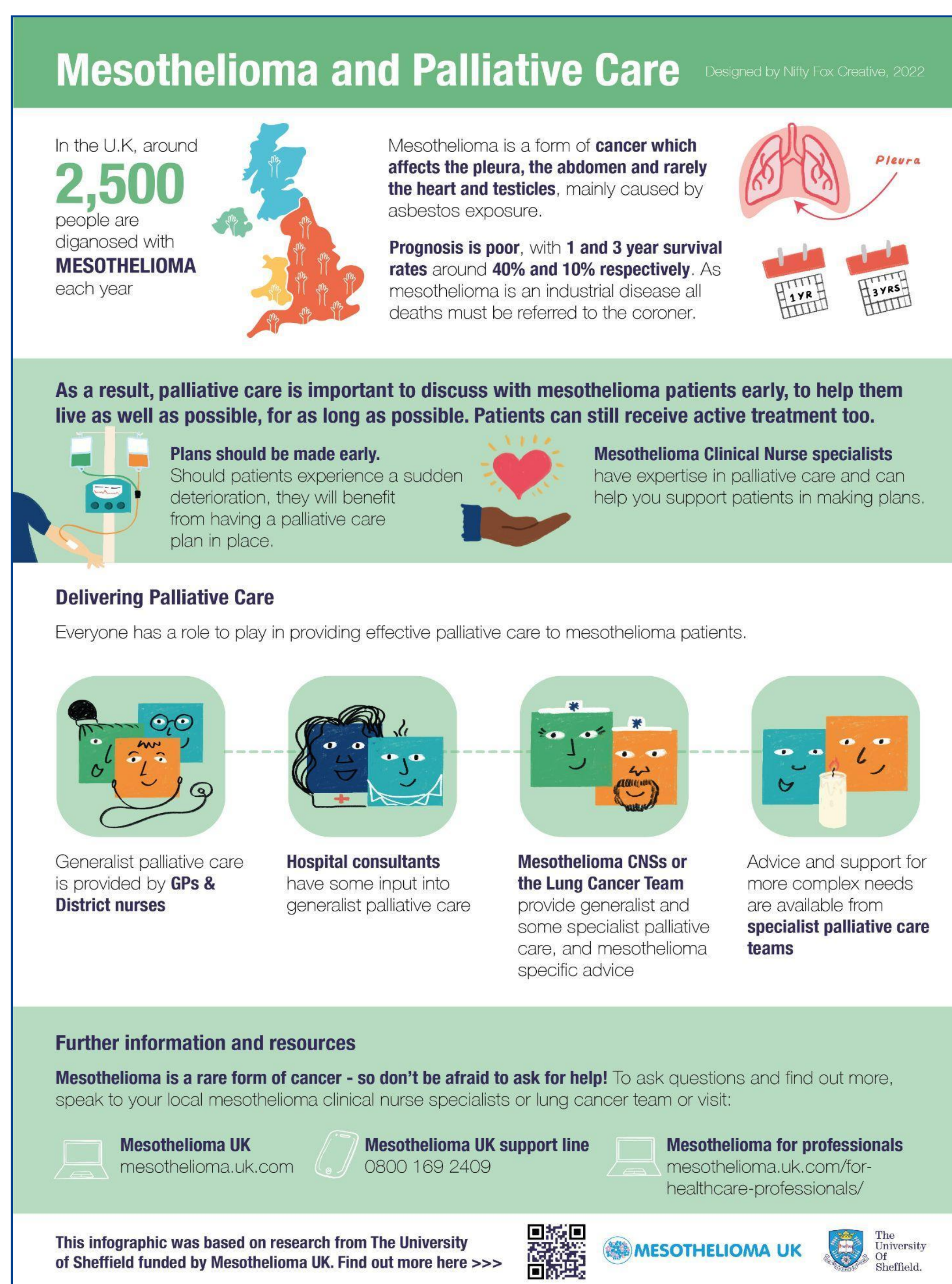


Figure 2: Infographic

<sup>1</sup>[www.sheffield.ac.uk/murc/our-research/palliative-care-and-role-clinical-nurse-specialist](http://www.sheffield.ac.uk/murc/our-research/palliative-care-and-role-clinical-nurse-specialist)

**Conclusion:** This work demonstrates the pathway from research to impact aimed at improving early-stage access to palliative care in mesothelioma. Initial engagement work at patient/carer events captured how views were changed after watching the animation. The tools are available on the Mesothelioma UK palliative care public and healthcare professional web-pages; and are being used by MCNSs as part of their clinical practice. Work continues to document and identify avenues to impact.



← Infographic

Animation →

