

# Holistic services for people with advanced disease and chronic or refractory breathlessness: a mixed-methods evidence synthesis

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## Plain English summary

Holistic services for people with advanced disease and breathlessness

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## Plain English summary

Over 2 million people in the UK are living with advanced disease and breathlessness, which can occur even when resting or performing everyday activities. Breathlessness can lead to feelings of panic and anxiety for patients and their family members. Breathlessness is hard to treat and drug treatments are of limited benefit. Non-drug treatments, such as breathing exercises or using a handheld fan, can often be used to good effect.

Some services offer a range of drug and non-drug treatments for breathlessness. These have input from different professional groups. They help patients and families cope with breathlessness by improving control and reducing distress caused by breathlessness. The aim was to bring together research about services for people with advanced disease and breathlessness.

First, the research team looked at how services are usually delivered and if they are acceptable, effective and offer good value for money. It was found that these services are delivered in a variety of ways, but, overall, they reduce distress caused by breathlessness and reduce depressive symptoms. Patients and carers particularly valued receiving education, learning simple tips to self-manage their breathlessness and seeing experts in person-centred care. Information on value for money was very limited and uncertain.

Second, the research team looked at research data from previous studies to find out which people are most likely to benefit (i.e. experience improvements in feelings of control and distress). It was found that people presenting with least control, or highest distress, were most likely to benefit. A person's main diagnosis, lung function or overall health did affect the likelihood of benefit.

Finally, a meeting was held of patient/carer representatives, researchers and health-care professionals. The findings above were discussed, and participants shared their priorities for health-care practice, policy and research. The top suggestions were sent out in a survey. People strongly agreed on seven priorities around providing flexible, person-centred care, sharing breathlessness management skills among staff and recognising informal carers.

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