

Active and Advanced Disease Workstream

Key Messages

Survivors with active and advanced disease face ongoing uncertainty. There is a need for the NHS and local services to be patient-centred, rather than disease-centred. Retaining some control of life is important to patients and well-being (emotional, physical, social, spiritual) is an issue.

There are also concerns about getting back into active treatment following recurrence, side-effects or other health problems.

The disease pathway for many will lead to end-of-life care. How should that expectation be discussed and when should proper EOL care be initiated in a patient-centred way?



What has the workstream been doing?

We have produced a series of papers on:

- The different patterns and phases of disease for patients with active or advanced disease - the natural history
- Patient-centred care and considered how needs in the primary care and community setting can be met
- Living with active and advanced disease – looking at issues of health, living, being and dying

We have held workshops on:

- Key worker or care manager/navigator roles
- Perceptions, expectations and needs in patient-centred care
- The transition to End of Life Care and the links with the Department of Health End of Life Strategy.

We have worked with the Assessment and Care Planning workstream to include patients with advanced disease in the testing of the assessment framework.

Next Steps

The priorities for the next phase of the workstream are:

Keeping well – identifying and sharing good practice in supported/facilitated well-being, social and emotional support. This includes assessment of need, navigation of services, information provision and access to well-being services (such as exercise).

Returning to the healthcare system – identifying and testing best practice for patients re-entering the health care system, for example at suspected recurrence. Looking at the need for clear pathways and a multi-disciplinary approach.

Transition to end of life – looking at assessment, communication and best practice, including patient and clinician perceptions and expectations