

What's happening with Daily Living? - Overview

The workshop aimed to enable participants to identify how they can become involved in designing and shaping social care services for people affected by cancer in their local area. It offered a chance to explore how to get more involved locally in the design and shaping of Macmillan Daily Living services such as social workers, befriending and emotional support and carers' services and in other health and social care services.

The workshop was interactive, and included an overview by the facilitators of Macmillan's Daily Living programme, and user involvement in social care in the UK (attached).

This was followed by an opportunity for delegates to share their knowledge and experiences of user involvement at a local level.

Key points

Some delegates had no prior experience of user involvement and were new to Cancer Voices, others are very experienced. Many have experience in health rather than social care user involvement but the boundaries are blurred. When users sit on a partnership group this may seem more health focussed but when they are campaigning for a benefits advice service, better transport, or a bereavement suite in a hospital, this seems to fit into the category of Daily Living (emotional and practical support for people affected by cancer).

Some delegates sit on the local LINKs group – very mixed feedback, the quality varies dramatically. Some people felt that the voice of local groups might not be heard now that LINKs has been introduced. People questioned the independence and efficiency of LINKs. Many hadn't heard of it.

Examples of delegates' experiences of user involvement:

- Setting up support groups for people with first languages other than English
- Working with health professionals and local MP to campaign on car parking
- Set up a CAB service in a health setting for cancer patients
- Self-management course for patients
- Partnership groups – educating professionals on how to break significant news, campaigning on car parking
- Consumer research panels
- Replying to surveys (note: user involvement doesn't always have to involve attending meetings)
- Campaigning for a bereavement suite in a hospital
- Campaigning for a family room in a hospital
- Campaigned for improved transport to hospital for treatment
- LINKs – mixed feedback on these

Issues arising from the workshops:

- You can use your experience/anger to make a change
- Macmillan should aim for a Cancer Voice in every PCT nationally
- There is a strong need for **advocacy** for patients and carers – someone to guide you through the range of services available including benefits and social care. One patient has been advocating on her own behalf to get help from social services – while undergoing treatment. The advocate should be independent, not a nurse or other health care professional.
- You have to be persistent; it takes time to make a change. One user lobbied for four years to get wording on a leaflet changed but she got there! You may not find the right type of user involvement. for you straight away – some people left groups, it wasn't working for them or the group.
- Delegates felt very strongly that the type of Daily Living services provided by Macmillan are essential. Also flagged up that they are unaware of them – need to promote and develop further. Questioned why they hadn't heard of these services when they needed them.

Barriers to User Involvement (UI)

- Living in a different geographical location so can't give feedback on patient care or services provided
- Limited time or capacity to attend meetings if in full time employment
- Cost of being involved, e.g. attending meetings
- UI can be London focused
- There need to be mechanisms in place to enable users to feedback in different ways e.g. email, letter, phone
- Meetings can be evenings, weekends, or daytime – but no one time suits everybody! Professionals don't want to work at weekends, older users don't want to go out at night.

Conclusions

Macmillan needs to work with Cancer Voices to highlight to people affected by cancer how they can make a change to social care, as well as health care, services. We need to make it clear how people can get involved, including ways that don't involve lots of travel, cost or meetings during work hours. We need to illustrate the range of opportunities – users could review a resource, help to make a DVD, respond to surveys, or gather feedback on a issue from their self-help and support group. We need to ensure that people are aware of their local LINKs group and how to get involved – and other mechanisms for the nations. We should also encourage our social care professionals to use the Opportunities Exchange to advertise opportunities for user involvement e.g. to invite users onto a steering group.