



Yes to Life

One•to•One Programme

A report on a new model of cancer care:
individual support provided by volunteers
with personal experience of cancer

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EXECUTIVE SUMMARY

A diagnosis of cancer can be a time of great turmoil and stress for many individuals and their families as they face an immense number of challenges that include physical, social, emotional, informational, spiritual and practical issues. It can be overwhelming, yet many individuals with cancer remain unaware of the possibility of taking a more proactive role in combating the disease and of the support services available to them.

In the current healthcare system, intervention is disease or symptom focused, frequently does not take into account the whole person and does not empower individuals to take an active role in their recovery. There is a lack of consistent and reliable information on complementary and alternative medicine (CAM) and people do not have equal access to it. Care and support for the client frequently stops when physical treatment ends and this has been identified as a peak time of vulnerability for the individual. As more and more people are living with and beyond cancer it is beginning to be regarded as a chronic disease and, as a result, greater emphasis needs to be placed on teaching strategies of self-management. Although there are charities providing high quality support, people often do not hear of them at the time of need.

The vision of Yes to Life is to provide an individual service of information, support and guidance through a network of trained volunteers, where a single volunteer can support individuals in taking an integrated approach to their treatment, drawing on the best of orthodox medicine and CAM: this is the One•to•One Programme. This one key volunteer, or guide, would be able to provide continuity of support from diagnosis, through treatment and into recovery.

Project description

The work described in this report covers four phases:

01

Phase 1 includes how the model of the One•to•One Programme and the method of delivery were developed through consultations with patients and key people in primary and secondary care and through learning from similar models.

02

Phase 2 describes how a pilot study was developed and delivered in primary care and the referrals that were achieved.

03

Phase 3 describes the proposed recruitment strategy and training programme for volunteers and the support structure.

04

Phase 4 describes the evaluation of the pilot: the findings, method of delivery and what has been learnt to take the Programme forward.

Phase 1

The initial intention was to pursue working in collaboration with secondary care, as this was seen as the best route to access large numbers of clients at diagnosis. However, it quickly became clear that there were difficulties with this approach at this first initial stage of development. First, we had no evidence to demonstrate the effectiveness or credibility of the Programme; second, there was some resistance to CAM and the integrated approach amongst the hospital team; third, there was the risk that the Programme would be constrained by the medical model and hospital bureaucracy, and fourth, the time it could take to establish a programme. For these reasons and because of time-constraints imposed by the budget, it was decided to run a pilot within primary care through GP Practices in The Royal Borough of Kensington and Chelsea.

Through these discussions, and after investigating other models of care, the One•to•One Programme emerged. The Programme is a positive new model of care that aims to empower individuals with cancer, through support and information, to find a path to recovery that is right for them, drawing on the best that integrated medicine has to offer. It is a model embedded in the client's community, taking advantage of local support systems and resources, and provided by trained volunteers in the locality who have personal experience of cancer. It provides individual, ongoing support to people, from diagnosis and into recovery and beyond. It also confers benefits on the volunteers, many of whom are themselves living beyond cancer, as the training has a strong focus on self-development and living healthy life-styles.

Phase 2

The two Project Leaders developed and delivered a pilot programme through eight GP practices in Kensington and Chelsea. The GPs were recruited through a staged approach to ensure demand did not exceed the resources. The Project Leaders each took on the role of a One•to•One volunteer in order to experience delivering the service and piloting the tools and materials, and also for expediency. It was also decided to limit the pilot to ten clients. A service framework and referral pathway were agreed with the individual GP practices following a presentation delivered by the Project Leaders.

GP referrals were slightly lower than had been anticipated. This can be explained partly by the small numbers of registered cancer patients on the practice lists, the lack of GP involvement once a diagnosis is made and the fact that not all GPs were equally supportive of the programme. Seven client referrals came via the GPs, five of whom became part of the pilot study. A further two referrals came via the Yes to Life website, two through direct referral from existing One•to•One clients and one from an integrated medical doctor.

Phase 3

The development of the recruitment strategy and training course for the volunteers drew on the knowledge of volunteer centres, the Mentoring and Befriending Foundation and volunteer projects providing similar models of care. These experienced organisations lent credence to our proposed One•to•One Programme being delivered by volunteers. The volunteer recruitment strategy includes targeted advertising in the local and cancer communities, an information session to ensure applicants have a full understanding of the role and commitment required and interview before the final selection is made.

The training course focuses on ensuring an understanding of the philosophy of the One•to•One Programme, the emotional cancer journey, the integrated approach to treatment and healing and developing the mentoring skills required to support an individual with cancer. The planned course and assessment for readiness to volunteer will take place over a three-month period. Overall, from initial advertising for volunteers to a trained team of One•to•Ones providing a service, will take five months. The recruitment strategy and training course have yet to be piloted.

Phase 4

The Programme was evaluated through feedback questionnaires from the participating GP practices, the clients and the observations and reflections of the two One•to•Ones delivering the service.

Key Findings from the Evaluation

- One•to•One support helps clients to help themselves, and timely access to information and resources empowers clients to self-manage. Most clients recorded feeling more in control, better able to deal with fears and more knowledgeable about ways to help themselves and about CAM resources.
- Funding needs to be available to ensure equal access to CAM information and treatments.
- Individual focus allows the support to be led by the client's needs, at their pace and in response to the stage they have reached on their cancer journey.
- Personal experience of cancer by the volunteers, and thus an understanding of the stresses involved, was valued by clients and some GPs.
- There was a marked high preference for being supported at home and not in a medical environment.
- Intensity of support provided to clients was higher at the beginning of the mentoring relationship and during phases of peak vulnerability.
- Many individual GPs agreed that an integrated approach to cancer care was positive and that they could see the benefits of One•to•One support especially where the clients had limited or no social or family network.
- The GP route alone does not give access to clients at time of need. Information and referral pathways need to be extended to diagnostic and specialist units.
- Clients who pro-actively self-referred to the service were generally more motivated and wanted to take a more active role in their treatment and understanding the choices available to them.
- Having the service based in a local community builds up knowledge of resources and support networks in that area, and will be logistically simpler in terms of time and costs when recruiting, training, managing and supporting teams of volunteers in the future.

Conclusions

The One•to•One Programme achieves what it set out to do, namely to support, inform and empower individuals coping with cancer and it is a credible model for trained volunteers to deliver.

A local community model shows many benefits in terms of knowledge of local resources and support near to the client's home. However, relying on GP practices for referrals may not provide equal access to the Programme by all clients in need.

Having the service targeted at high risk phases such as at the point of diagnosis or at the end of treatment is seen as a potential way of developing the service in the future. Information and referral pathways need to be available within the diagnostic units of the hospitals and awareness of the Programme needs to be raised amongst those working in the field.

As the findings of this evaluation are based on a relatively small and localised sample a larger study is recommended in order to develop robust evidence of effectiveness to ensure the Programme's sustained funding and future growth.

Yes to Life

Yes to Life, set up as a charitable company in January 2006, is dedicated to making the widest range of complementary and alternative medicine available to those with cancer in the UK. To deliver their promise, Yes to Life has developed three key services:

1. HelpCentre, which includes a Helpline as well as Individual Patient Funding
2. One•to•One, which provides emotional and practical one to one support from diagnosis, through treatment and beyond.
3. Searchable Online Directory of complementary and alternative cancer treatments.

Yes to Life also funds complementary therapists to work on the cancer wards and day centre at UCLH.