

# **Making the biggest difference: supporting cancer patients**

Research Report

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## Introduction

This research was inspired by knowledge of cancer patients' experiences shared by the Macmillan Benefits Advice service at Toynbee Hall. Toynbee Hall is a 130-year-old community organisation that gives some of the country's most deprived communities a voice, providing access to free advice and support services and working with them to tackle social injustice. For the last four years, we have provided Macmillan benefits advice services for cancer patients and their families living in Tower Hamlets, Newham, Hackney and The City of London. As well as at Toynbee Hall itself, we provide these services at St Bartholomew's, Newham University and Whipps Cross Hospitals. We have recently expanded this service to include both The Royal London and Homerton Hospitals. From May to July 2015, a team of postdoctoral and postgraduate researchers at Toynbee Hall conducted this study which was funded by Healthwatch and the NHS CCG Tower Hamlets.

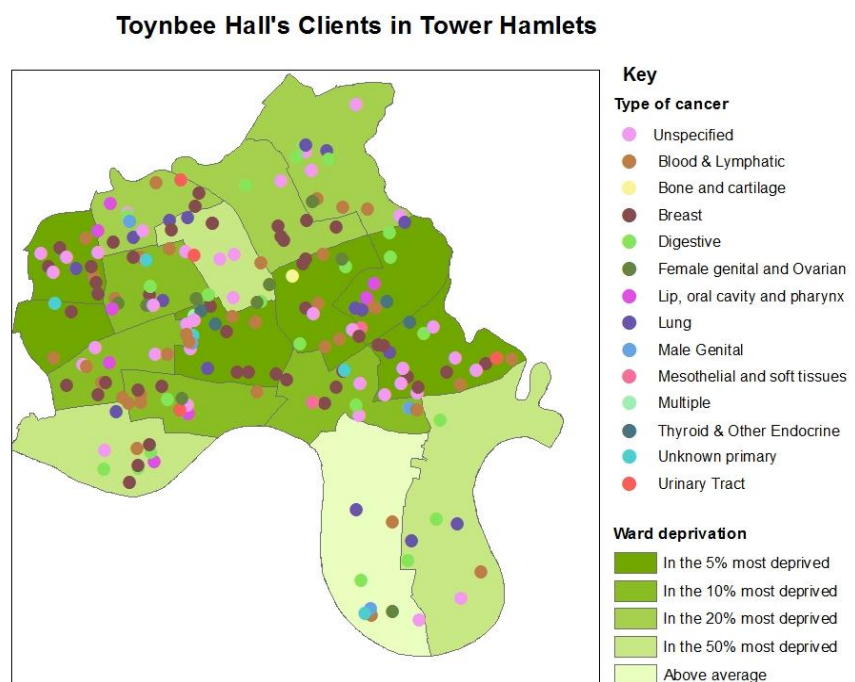
Cancer can change lives in many ways as suggested by many studies. It presents different challenges to other illnesses, involving substantial fatigue and loss of energy (Stone et al, 2000); treatment including chemotherapy and its disruption of people's lives (Hubbard et al, 2010); a challenge to personal identity and a sense of normality (Sandsund et al, 2013); significant fear and confusion about the disease and its symptoms (Clarke and Everest, 2006); and the growing new challenge of treating survivors of cancer (Richardson et al, 2011). This indicates the multiple types of needs of people with cancer and their families.

Understanding patients' needs is rarely translated into direct recommendations for services. So in this research, we aimed to explore the kinds of support that would make the biggest difference for people with cancer and their families, and we hope to provide recommendations that could be shared directly with service providers. We asked the following questions to address the research aim:

- What support do cancer patients require?
- What services are available?
- How can services be improved to provide greater support?

## Our approach

A combination of qualitative methods and GIS mapping was used to address the research questions. Our GIS maps provide a visual overview of where cancer support services are based. We firstly mapped the locations of 1182 anonymised Toynbee Hall clients, approximately 200 of whom live in Tower Hamlets (see right). We added another layer to show the poverty in Tower Hamlets based on the Index of Multiple Deprivation (Department for Communities and



Local Government, 2011). Different types of services were then identified in the map to show their availability in socially-excluded areas in Tower Hamlets.

To explore their lived experience, we also conducted interviews and a focus group with cancer patients and their families. Sixteen people took part. They came from diverse backgrounds and varied in terms of age, gender, ethnicity, marital status, stage of cancer and cancer type. Thirteen of these respondents were cancer patients and three were patients' family members. To protect their anonymity, all names used in this report are pseudonyms.

As researchers at Toynbee Hall, we were able to access cancer patients and their families who use services provided here and who are often socio-economically vulnerable. However, the researchers' impartiality was emphasised as we wanted to hear about both good and bad experiences. Additionally, six respondents were recruited from hospital clinics and a health workshop, ensuring that the findings would not be limited to our organisation's client group alone.

We made efforts to ensure respondents benefitted from their participation. We signposted or referred some participants to relevant services at both Toynbee Hall and other organisations. The fieldwork itself also proved beneficial to some participants simply because it offered an opportunity for them to be heard. One participant, for example, noted: *Now that I am talking to you, I am taking a lot of my [negative feelings] out, I feel so much better, in myself. (Linda)*

## Findings: making the biggest difference

The following sections present key findings of the research. We begin with a case study, Linda's story, which draws out the key themes of the research, and proceed to examine these themes in more detail.

### Linda's story

Linda is a Cypriot woman in her 60s who lives alone. She was diagnosed with cervical cancer in 2009 and Non-Hodgkin lymphoma in 2013. Following the researcher's introduction, Linda's recollection of her cancer journey focussed on a lack of support:

*Nobody came to see me, nobody asked me if I needed anything, nobody helped me in any way at all. ... No services at all. ... It chokes me up just to think about it. (Linda)*

Sharing how she was told about her first cancer, Linda said:

*When I opened the door, she [my GP] didn't ask if I was with anybody, she didn't ask me to sit down. ... You can imagine my shock: I'm standing at the door and this doctor is telling me that I've got cancer. What do you do? (Linda)*

*My father was only round the corner. I could have rung for somebody to come. It would have taken two minutes. But I wasn't given the opportunity. (Linda)*

So Linda felt that her GP had failed to consider her feelings and potential support need. But subsequently, Linda also described more positive encounters with other medics. What made a doctor or nurse 'good' for Linda centred on their attitude towards her:

*For you [the doctor] to give a smile, you give encouragement to that person, to go on with what they have to go on with. (Linda)*

Sharing smiles, having a positive attitude and giving encouragement to face up to cancer were mentioned repeatedly by Linda and some other participants. These seemed especially important to patients during treatment.

Cancer has changed Linda, from 'a very outgoing person' to someone who does 'not leave the house':

*I am ... afraid to catch an illness. (Linda)*

*If I don't go out anywhere, I don't spend any money. And when I go shopping... I can't spend more than £20. So I make sure what I buy is enough to see me for the whole week. (Linda)*

For Linda, fear for her health and financial difficulties mean she has to 'stay at home 24/7'. Her account strongly calls for financial assistance as well as psychological and social support for her, especially considering she does not have close contact with family and friends.

Linda's story underlines the types of support that would make the biggest difference for the respondents in this study. Like Linda, many of them require new and various forms of support to face the changes and challenges which cancer brings. Such support includes being treated with understanding and positivity, having someone to talk to, resolving money worries and integration of services. The following sections will discuss these areas in detail.

## **Understanding and positivity**

All but one of the cancer patients took part in the research had suffered from fatigue and loss of energy. All had side effects from treatment or secondary symptoms of cancer: on average four were reported per person. The participants noted that 'sincerity' (Zariya) and positivity help them cope better with the draining physical impact. Health professionals play a big part of their journeys, so doctors and nurses' accounts placed great importance on this need and this research suggests that they are largely helpful.

Some participants talked about the importance of clear communication, with positive accounts of the step-by-step explanations provided and more negative descriptions stressing the lack of clarity. Different experiences suggest the importance of patient-centred care that provides information that patients require and communication that suits their needs. Robert, a bladder cancer patient, for instance, described a negative experience. He felt treated 'as a body' rather than as a person. His examination was intrusive and onerous to the extent that he delayed re-examination when he noticed symptoms returning:

*It makes my eyes water thinking about it [the examination]. They've got to put a camera up your penis ... and you're lying down, and there's like, four or five people round you. ... You feel bad in yourself for letting all these people round you messing with you. (Robert)*

Robert found the examination process particularly challenging because of the location of his cancer: for him, the process was almost intolerably intrusive. He suggested that offering general anaesthetic as an option for patients undergoing sensitive examinations would be a way around this, which suggests a need for clearer communication of the rationale behind examination methods, perhaps including alternative approaches, and clearer consideration of the psychological impact on patients.

For a few other respondents, understanding their needs meant understanding their difficulty of waiting for three hours for a chemotherapy session. They said that it takes six hours to complete a session of treatment and they are often exhausted by the time they complete the treatment and make their way home. Reducing the waiting time would have been a clear improvement for them. St Bartholomew's Hospital, for instance, has been making efforts to do so.

Some other people also highlighted the importance of a positive attitude among health professionals, from a simple smile emphasized by Linda and Beatrice, to the demonstration of an expectation of success:

*'Right, ok, we're going to fix this' – an expectation of success, ... a very upbeat attitude is really helpful. (Debbie)*

Debbie is a White Irish woman in her 40s whose husband Chris has cancer. She has epilepsy and receives benefits, which Chris used to manage for her. Since his diagnosis, however, Debbie has had to take on the caring role and acts as the 'healthier' person in the family. The couple both benefited from the upbeat attitude of the doctors and nurses, the 'feeling of them genuinely wanting you to get better' (Chris). Staff's friendly, reassuring faces also helped them to get orientated in the otherwise new and confusing hospital environment.

For some respondents, the understanding and positive attitude also need to come from their families, friends and the general public. David, a White British man with stage 3 colorectal cancer, for instance, strongly argued that the characterisation of cancer as something to 'fight' was unhelpful:

*They seem to characterise the experience of having cancer ... as what they call 'a fight'. As far as I'm concerned I'm not having a fight with anyone or anything. I'm just having some treatment. ... It colours people's attitudes. (David)*

David suggested that cancer patients were seen by families, friends, colleagues and the public as 'different'. Considering that one in three people will be diagnosed with cancer at some point in their lives (Tower Hamlets NHS CCG, undated), ensuring that cancer patients can feel 'normal' and supported in facing the disease and continuing their everyday lives is particularly important.

Raising the public awareness of cancer seems to be often mentioned in policy making. But most participants in this study suggested they had a good level of aware even before their diagnosis. What they considered more important is in fact encouraging the positive public thinking on living with cancer.

### **Having someone to talk to**

In addition to the need for understanding and positivity, the respondents' accounts underlined the need for psychological and social support. Such support is needed by both patients and their families. It 'is big' (Ali, Joan) and provides 'an outlet' (Debbie) and a way to think through the implications of the illness.

Family members often provide psychological and social support, but our interviews suggested that such support can be limited. Some people did not want to burden or worry their family; some found that their family did not understand them; and some simply do not have any family around. Support from someone outside the family is therefore important.

Some respondents, such as David and Mark, highlighted the importance of psychological therapy and workshops. But sometimes, other patients can also be a good source of psychological and social support. This was emphasised in our interview with Joseph, a fiercely independent older man having previously worked as a nurse:

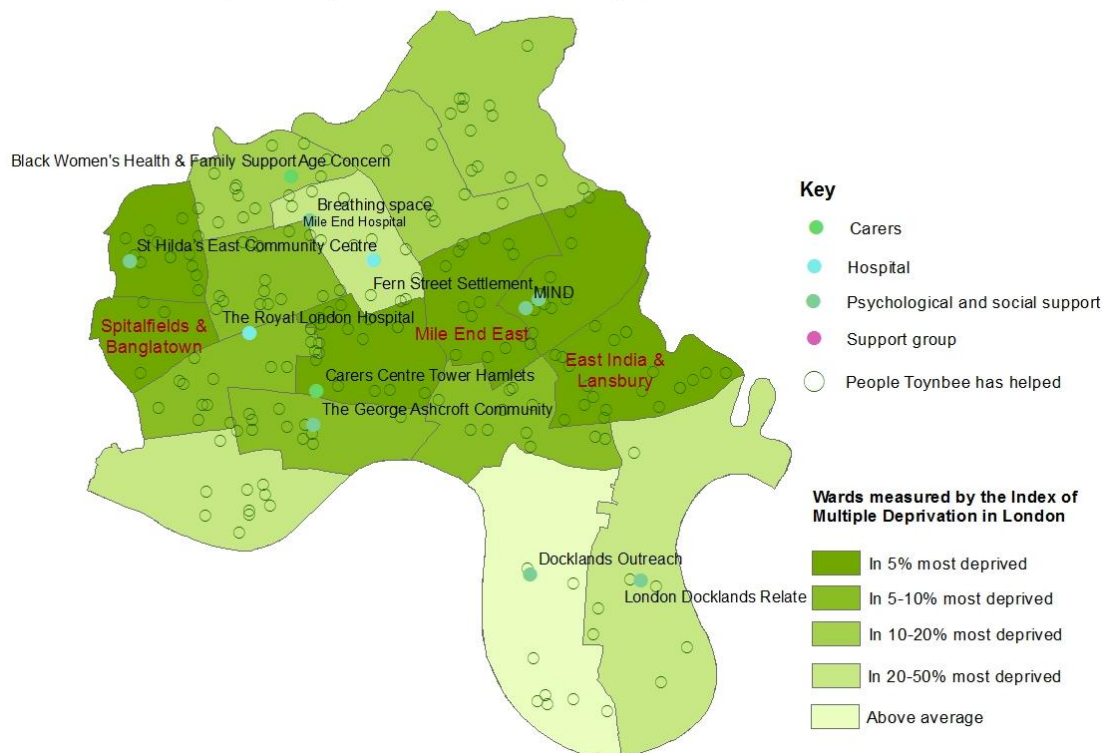
*By speaking with the patients who had the same cancer treatment ... you feel much better, you talk it out (Joseph).*

We recruited Joseph through a health workshop at St Bartholomew's Hospital. Gathering all the different services, the workshop seemed to mentally prepare the patients and encourage interaction between all the patients who had cancer at different stages.

Hospitals and organisations could therefore create more opportunities to encourage patients to support each other. One solution could be to set up a befriending scheme where volunteers who have recovered from cancer support patients in the hospital through the different stages of their cancer journey. This idea was inspired by some respondents who were grateful for Toynbee Hall Macmillan services and were happy to provide any help needed.

In addition, support groups could be helpful for some cancer patients. But, surprisingly, through our mapping of psychological and social support services, no support group specifically for cancer patients can be identified (see map below). This seemingly suggests a gap in service provision.

### Psychological and Social Support in Tower Hamlets



From this map, we would also like to draw attention to the lack of psychological and social support services for people with cancer in three wards: Spitalfields and Banglatown; Mile End East; and East India and Lansbury. These three are among the 5% most deprived wards in London, suggesting a greater need for local service provision. It is also worth noting that there are other community organisations not identified in the map as they do not offer specialist psychological support but may be able to provide support networks for people. Information on or referrals to these organisations can be provided to cancer patients so they can receive at least some levels of support in their local areas. Relationships can then be developed between such organisations and hospitals to improve the quality of support.

### Resolving money worries

The third area of support that participants emphasised was that of financial assistance. Macmillan Cancer Support (2012) estimates that 91% of cancer patients' households experience a drop in income. In this study, apart from those who had already retired or been unable to work because of other illnesses, all the cancer patients and family members had to either stop working or reduce working hours. They therefore believed that it was 'foundational' (Debbie) to receive help in resolving their money worries.

Ali was one of the respondents who talked at length about his loss of income. He recalled that the first two to three months after his diagnosis were his *'most difficult time'*:

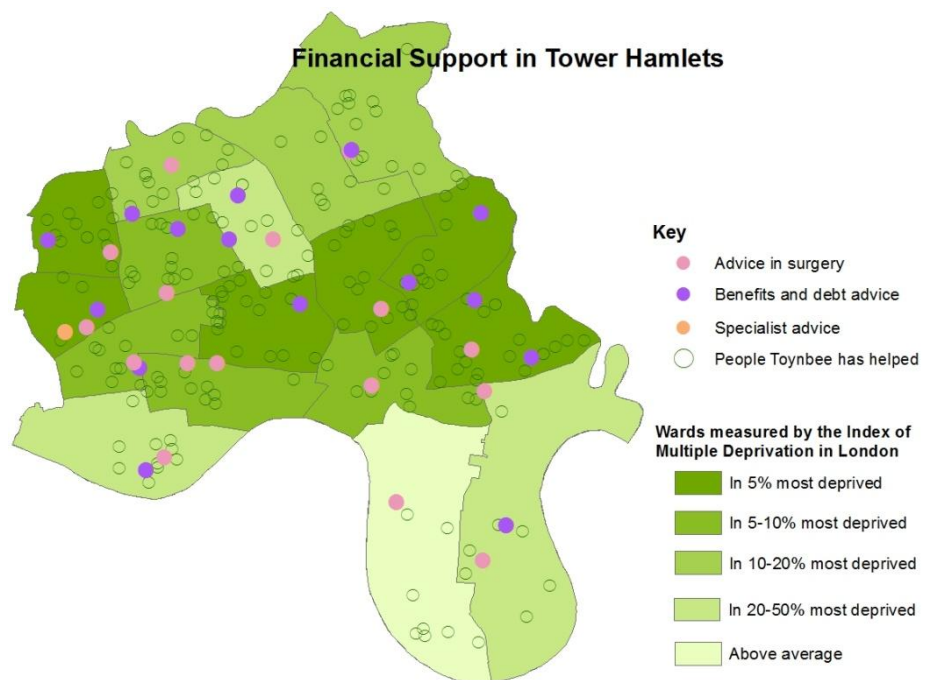
*I was in a very bad condition, because I was not able to pay my bills ... £700 is a big money if I don't have a job and the same time I have a family ... I have to feed them. (Ali)*

Ali is a Pakistani man who had always worked, supporting his wife and three children. More than his health, he worried about the impact of not being able to work: having no money to support his family and the possibility of losing his home because of rent arrears. Ali relied on a bank overdraft during that period and received help from a Macmillan benefits advisor to stabilize the situation and maximise his income. This support made a great difference to Ali's life and he noted that the first payment of £300 *'was quite a help'* and *'big money for that time'*.

A few respondents noted the complexity of the benefits system. Some described benefit claim forms as *'booklets'* that were *'confusing'* (Linda, Beatrice), particularly problematic in the context of treatment that reduced their energy levels. Some also experienced debts which worsened their situation. As a result, the financial support and benefits advice participants had received were commonly appreciated. Although participants were recruited from other services as well as Toynbee Hall's Macmillan benefits advice service, most had received financial support and benefits advice. We can only speculate about the situation of those without access to such advice: further research would be required to understand their experience.

Our mapping of benefits and debt advice services (see below) shows there is only one specialist advice service in the borough specifically helping cancer patients. This service is Macmillan benefits advice currently provided by Toynbee Hall. Macmillan Cancer Support funds the service on a yearly basis on the condition that the funded organisation tries their best to secure alternative funding or match funding. It is therefore important to address the question of where the alternative funding is.

The map of financial support also shows a wide spread of other benefits, debt and generalist advice services in the borough. These services are not targeted at cancer patients. So whether cancer patients use these resources, whether the services meet their needs and how a good referral channel can be built between Macmillan benefits advice and other advice providers are also questions that remain to be addressed.





## Integration of services

The key to receiving the different types of support discussed above is the integration of services. Most respondents had multiple needs and issues. Many of them had benefits issues; Prem, Mark and Linda had housing problems; Zariya had a child care issue because her five-year-old daughter was not allowed in the hospital; and Prem, who had recently completed his chemotherapy, wanted to learn about setting up a business which would allow him to work following his recovery. This range of issues demonstrates the variety of needs among people affected by cancer. Integrated services are required to provide 'one-stop' access to support.

Among all our respondents, Ming, a Chinese man in his 40s resident in Britain for 20 years, might have the least support as he speaks no English and has no family in this country. The tests Ming had in Britain indicated no signs of cancer, but after collapsing at work, he flew back to China to be diagnosed with advanced pancreatic cancer. He did not go to A&E because of his test results and the language barrier. He has been given less than 5 years to live.

Ming used to own a Chinese takeaway but had to close it down due to his ill health. Having now spent his savings, he has no money and nowhere to live. In the last two years, he lives with friends in London, sometimes having to share a bed, and says his local council has been avoiding its legal duty to house him.

Talking about support, Ming said:

*I am alone in Britain. ... I have no one here, even to burn my body [when I die]. (Ming)*

*He [the benefits advisor] is the most important support for me. He cares about me so much; you see, before I even thought of contacting him, he wanted to see me. (Ming)*

Ming's need for financial, housing and psychological support is clear, but his benefits advisor is the only support he has. The advisor has helped Ming to apply for benefits and provided psychological support to some extent; he has also helped Ming make contacts to deal with his housing issues. Ming's experience highlights the lack of integrated services and the difficulty that it brings to people's lives.

As discussed earlier, there is a wide spread of generalist, benefits and debt advice services in the borough. There are also approximately 60 community centres listed by Tower Hamlets Council; health trainers have access to around 50 venues; and older people's services could also be suitable for many cancer patients. These examples suggest that services are available, but not necessarily integrated and well-used by people with cancer and their families. People might not be aware of these services as they have not needed them before. As Debbie recalled, '*I was in a totally confused state. I wouldn't have known who to go to at that point*'. Since Macmillan services were commonly described as being helpful and '*in the right place*' (Zariya, Debbie), we suggest that Macmillan could be used as an initial point of contact and a platform to refer onwards to other services. An information pack or a personal calendar app as suggested by David could be also helpful in allowing people to access all relevant service information in one place. A personal calendar app could be also valuable for appointments and general hospital administration.

It is important to note that people often require information about services at the beginning of their cancer journey. Debbie, for instance, noted that:

*For something like cancer, which seems to be fast in development and with treatment, having an awareness of what's out there before you actually need it is important. (Debbie)*

Debbie's comment was echoed by many others. While it may be difficult to anticipate what support people will require during their cancer journey and whilst needs vary at different stages, respondents noted the value they placed on being prepared for their experiences. Linda recalled that her ability to absorb information was limited at certain stages, such as during chemotherapy, and this barrier has been noted in previous research (Echlin and Rees, 2002). Providing service information on diagnosis therefore supports patients to gain access to relevant support when needed at later stages.

## Recommendations

This research identifies the types of support that would make the biggest difference for cancer patients and their families. Such support includes being treated with understanding and positivity, having someone to talk to, resolving money worries and integration of services. Based on the findings summarised in the previous sections, the following recommendations have been identified, divided into short, medium and long term goals:

### Short term:

- Hospitals should develop strategies to reduce patients' waiting time for treatment sessions, such as that for chemotherapy.
- We should investigate starting a support group in the borough or building on existing social groups. Such social support would be very useful especially for the large number of lung cancer patients in the borough and in the three wards identified earlier (Spitalfields and Banglatown; Mile End East; and East India and Lansbury).
- There needs to be an information pack which is updated regularly. The pack should include main services such as psychological and social support services, generalist, benefits and debt advice, exercise groups and older people's services. This information pack can be given to the patients at the point of diagnosis.

### Medium term:

- Further training should be provided to help both doctors and nurses understand patients' experiences and develop better and more positive communication skills.
- Hospitals, Macmillan or other support services could set up a befriending scheme where volunteers who have recovered from cancer support patients in the hospital.
- Funding sources for cancer advice services need to be diversified.
- Macmillan can act as an initial point of contact and be more proactive in referring people onwards to other services.

### Long term:

- Health providers should work with the media, encouraging positive thinking on living with cancer.

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