More than just transport...

Transport as a Practical and Psycho-social Support for People with Cancer

Research by Purple House Cancer Support
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Executive Summary

Introduction
This research explores the community based transport service provided by Purple House Cancer Support to people accessing the Cancer Treatment Centres in Dublin. It has been commissioned by Purple House Cancer Support and written by Mags Crean & Ciaran Carroll.

Field Research
A combination of surveys (n=42) and interviews (n=7) were conducted with Purple House Cancer Support clients. Participants for the surveys and interviews were selected using Purple House Client database.

Overview of transport service
The demand for the transport service has been increasing by approx. 10% each year. From 199 trips in 2010 to 409 trips in 2014. In 2014 the transport service cost approx €25,000 to operate. This is financially supported through fund-raising activities and receives no statutory financial support. This is highly cost-effective when the financial, practical and emotional costs are factored into alternative private and public transport options.

Literature and Policy Review
Recognising that transportation to and from treatment is often one of the most difficult challenges cancer patients face. The literature shows that transport support is more than just a practical support and is a psycho-social support. Irish policy, funded through the NCCP, has identified transport as a significant support issue for people with cancer.

Findings and Discussion
The research found that:
1. Community provided transport for cancer patients is more cost effective.
2. Cancer patients view Purple House Cancer Support transport service as a vital support during treatment.
3. The future of Purple House community transport service is limited by lack of government support.

Recommendations
The research report makes 6 recommendations related to transport policy and procedures; financial sustainability of the service and future development of the service. The need for a secure and sustainable source of funding is concluded as the most appropriate way that Government can support community based supports to address transport needs for cancer patients.
1. Introduction
This chapter provides a background to the research as well as an overview of the research methodology and structure of the report.

1.1 Background to Purple House Cancer Support
Purple House Cancer Support is a registered charity in Ireland (number 12589). We provide cancer support services and facilities free of charge to people affected by cancer in the Dublin, Wicklow and Leinster areas. The Centre has been in existence for over 25 years. From humble beginnings around a kitchen table in Bray in 1990, Purple House Cancer Support was the first community based cancer support centre of its kind in Ireland.

Founder Veronica O’Leary had identified a gap in the health services for people with a cancer diagnosis and she focused the service on psycho social and psychological issues and practical support such as counselling, transport, home support, statutory entitlements, family support etc.

Approximately 20% of funding for Purple House Cancer Support comes from the HSE. The remaining 80% comes from fundraising events & donations. Purple House works in partnership with the HSE, the medical profession, the Irish Cancer Society and other relevant agencies. It is independently governed and operated and it is not funded by any national cancer organisations.

1.2 Background to the research
This research explores the community based transport service provided by Purple House Cancer Support to people accessing the Cancer Treatment Centres in Dublin. It has been commissioned by Purple House Cancer Support and written by Mags Crean & Ciaran Carroll.

Transport to and from appointments benefit the patient and the family while also reducing anxiety and stress, particularly when the volunteer driver is experienced, adequately trained, and receives appropriate supports.

The Government has initiated the consultation process for the third National Cancer Strategy for 2016-2025. Practical supports like transport need to be central to a psycho-social and community based approach to cancer support. This research will provide an evidence-base to make the case for the critical role that a practical support like transport can play in the cancer journey.
The research had the following **aims**:

1. To assess whether community provided transport for cancer patients is more cost effective.

2. To explore whether cancer patients view PHCS transport service as a vital support during treatment.

3. To examine the future of Purple House community transport service and the limitations to development posed by a lack of government support.

### 1.3 Methodology

#### Data collection

A combination of qualitative and quantitative research methods was used to collect data for this research. A survey was designed and completed with 42 clients of the report service. Seven one-to-one interviews were held with Purple House staff. A set of open ended questions was designed for the interviews. Participant observation was also utilised to gain a greater insight into a typical hospital journey.

#### Participants

Participants for the surveys and interviews were selected using Purple House Client database.

#### Data analysis

The survey data was collected using survey monkey. It was analysed using the survey monkey tools. The interviews were recorded, transcribed and then analysed for themes.

#### Literature review

A review of policy documents and literature was conducted on the issue of cancer supports and cancer services with a specific focus on transport.

### 1.4 Conclusion and structure of the report

The report is divided into four sections. The first section introduces the transport service and provides an overview of usage and costs. The second section gives a detailed overview of the policy context. The last two sections present findings from the field research and practical recommendations for Purple House Cancer Support arising from the field research results.
2 Overview of Purple House Cancer Support transport service
This chapter provides an overview of the transport service including an overview of data and costs incurred.

2.1 Policy and process
The transport service is free of charge and fully accessible. The referral process involves hospitals and healthcare professionals referring clients to Purple House or clients doing self-referrals.

The service provided includes transport of clients to the Blackrock Hospice, St. Vincent’s Hospital, St. Luke’s Hospital, Blackrock Clinic, The Beacon Hospital, St. Colmcille’s Hospital, St. Michel’s Hospital and to Purple House Cancer Support. Forty per cent of referrals come from St. Luke’s hospital.

Regular peer support and meetings with the CEO are held every month to 3 months. There are 12 voluntary drivers. Purple House recognises that the volunteer drivers need to be properly trained and supported in dealing with clients and debriefed when their service with a particular client is no longer required e.g. the death of a patient.

The Policy of Purple House Cancer Support around the recruitment and selection of a Volunteer Driver is usually by word of mouth, or someone that is known to the Centre and has benefited from the Service, or is involved with another organisation i.e. Retired Nurse, Citizens Information Centres etc.

Induction training on the policies and procedures of Purple House is initially offered and peer support is provided by an experienced volunteer. A probation period is put in place and reviewed regularly. On-going training and supervision is provided along with other training needs as arise e.g. Manual handling, Listening Skills etc.

The Policy of Purple House Cancer Support is to reimburse out of pocket expenses for fuel, parking and any other costs involved in the transport of a client.

2.2 Aims of the transport service
The transport service in Purple House has a number of aims:

- To improve the quality of life, for those living with cancer and their families and friends;
- To reduce anxiety around getting to appointments; and
- To make life as easy as possible for those clients who come to Purple House.
2.3 Increasing demand for transport service
The demand for the transport service has been increasing by approx. 10% each year. From 199 trips in 2010 to 409 trips in 2014.

2.4 Costs and financial support
In 2014 the transport service cost approx €25,000 to operate. This is financially supported through fund-raising activities and receives no statutory financial support. Table 1 outlines the cost-effectiveness of this community service:

<table>
<thead>
<tr>
<th>Possible Journey</th>
<th>Taxi cost</th>
<th>Public transport</th>
<th>Personal travel cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>To and from St. Luke’s hospital</td>
<td>€53 with specialised disability taxi service €65 private taxi service</td>
<td>No direct public transport to St. Luke’s hospital</td>
<td>Emotional and physical stress of travel; parking costs; petrol costs circa €30</td>
</tr>
</tbody>
</table>

Table 1: Travel costs to and from hospital

Research by the Irish Cancer Society found that almost eight in every 10 (79%) cancer patients had costs in relation to transport to hospital appointments. 72% paid for travel and 52% for parking. On average, these amounted to €360 and €75 respectively. The percentage with travel expenses fell with increasing patient age.

There is very little financial support for transport. The following table highlights possible options and illustrates the limited financial support for transport for individuals. It also highlights a gap at a community level in statutory funding of transport needs of cancer patients.

<table>
<thead>
<tr>
<th>Social protection</th>
<th>HSE</th>
<th>Charities</th>
<th>Irish Cancer Society</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community Welfare Officer can be approached for travel costs; mobility allowance and the motorised transport grant are no longer available.</td>
<td>There is a limited bus service for hospitals</td>
<td>Charities such as the St. Vincent de Paul are often approached for support</td>
<td>NCCP funded Travel to Care programme.</td>
</tr>
</tbody>
</table>

Table 2: Possible financial supports for hospital transport
2.5 Conclusion
This chapter has highlighted the growing demand for Purple House Cancer Support transport services amidst the high costs of alternative costly options and the lack of Government support at a community level for transport needs. The cost effectiveness of the transport service is clear in contrast to alternatives.
3 Policy context and literature review

This chapter examines the Irish policy context for cancer support services as well as literature that highlights the role of transport services in the cancer journey.

3.1 Cancer policy in Ireland

The National Cancer Care Programme underpins cancer supports and services in Ireland since 2006. A large focus within cancer policy has been the development of formal psychosocial support services. In addition, the NCCP identified the importance of practical help, for example dealing with everyday concerns of patients and their families in relation to financial strains, hidden costs and transport issues.

The voluntary sector in Ireland has, to date, been the mainstay in the provision of supportive care for cancer patients in the community.

3.2 Literature on transport support and cancer

Most people living with cancer will deal with issues that cause stress. Stress is experienced from the initial diagnosis, to discussions of prognosis to treatment discussions and then practical considerations about travelling to appointments. While many patients cope well, a high proportion develops significant psychosocial distress. More than a third of patients experience anxiety and/or depression (Trill, 2013). Most hospitals and oncology services are not currently set up to support patients to the degree needed to offset the psycho-social impact of cancer. Evidence shows that when people experiencing cancer receive good social and psychological support, their quality of life improves. The majority of this support is provided at a community level.

Transport support is a very practical support provided at a community level and is part of a continuum of psycho-social supports. Because of the side-effects of cancer treatment, patients can find it distressing or difficult to travel by public or hospital transport services, even if these are available, making them very reliant on private cars, taxis, etc. Research from the UK and other countries has highlighted the costs of travel and related expenses (e.g. meals) experienced by patients and their families (Houts et al, 1984; Cohn et al., 2003; Lauzier et al., 2003; Allirajah et al., 2005; Heath et al., 2006; Owusu-Barnaby et al., 2006; Longo et al., 2007).

For example, a study by MacMillan Cancer Support in the UK, published in 2006, found that 70% of patients faced extra costs in getting to their treatment and the average overall cost of travel and parking per patient was £325k (Owusu-Barnaby et al., 2006).
The out-of-pocket expenses incurred by patients are not the only concern relating to travel.

Qualitative research in Scotland suggests that various aspects of treatment-related travel and transport are associated with cancer-related fatigue and anxiety (Hubbard et al., 2006). There is also the possibility that travel costs, or other travel-related issues, such as transportation difficulties or being away from social support networks, might impact on clinicians' treatment decision-making, or patients' compliance with treatment (Payne et al., 2000).

Some studies in the USA have suggested that problems with transportation may lead some patients to forgo treatment (Goodwin et al., 1993; Guidry et al., 1997). In the UK, one study found that patients living longer distances from specialist centres were less likely to receive surgery, chemotherapy or radiotherapy (Jones et al., 2008).

It seems clear that the issue of patient travel, and related issues (e.g. costs, access to appropriate modes of transport, need for overnight accommodation, meals, arrangements for family members) should be a central consideration in the re-organisation of cancer services in Ireland.

3.3 Transport funded programmes in Ireland

The introduction of a NCCP-funded scheme to provide assistance with transportation costs for patients attending designated cancer centres is to be welcomed.

This scheme, known as Travel2Care, was implemented on a phased basis consistent with the transfer of cancer services to the designated cancer centres. Initially, individuals diagnosed with breast cancer were entitled to claim financial support for travel costs related to diagnosis and treatment. The scheme is being facilitated by the Irish Cancer Society. Further roll-out of the Irish Cancer Society Care to Drive volunteer driving service for cancer patients (Irish Cancer Society, 2010b) also has the potential to help alleviate the difficulties patients experience in travelling by public or hospital transport.

There are, in addition, a range of actions that individual hospitals may engage such as offering, or extending, subsidised parking schemes for oncology or radiotherapy patients, and/or providing meal vouchers for those required to spend a long time on day wards.

Travel-related areas that were explored by the NCCP include: (1) the financial and emotional burden of travelling long distances from home for treatment; and (2) whether the distance that a patient lives from a designated cancer centre affects clinicians' treatment recommendations or patients' treatment decisions or compliance.
The Irish Cancer Society offer two transport programmes; Care to Drive: a transport service for patients and Travel2Care: a funding for transportation costs. The Care to Drive programme is a volunteer service and the Irish Cancer Society maintain that there are many hidden costs associated with running a national transport programme – volunteer expenses, advertising for new volunteers, awareness campaigns for clients and many other charges that can add up.

The National Cancer Strategy "A Strategy for Cancer Control in Ireland “ published in 2006, recommended that all major cancer treatment be delivered in eight designated specialist cancer centres and approved satellite centre. The HSE’s National Cancer Control Programme (NCCP) has responsibility for the implementation of the Strategy and this will involve overseeing the transfer of all major cancer diagnostic and surgical treatments to the designated centres.

Some people who are referred to a designated cancer centre may need help with the costs of travelling to their appointment(s). This is a fact recognised by the NCCP. As a result, the NCCP has agreed to fund a Travel2Care scheme that is managed separately by the Irish Cancer Society on behalf of the NCCP. The aim of the scheme is to help patients with some travel costs if they have genuine financial hardship or need due to travelling to a designated cancer centre or satellite centre. Travel2Care will provide some financial help towards the costs of public transport such as trains or buses, private transport costs; or petrol and parking.

3.4 Conclusion

Recognising that transportation to and from treatment is often one of the most difficult challenges cancer patients face. The literature shows that transport support is more than just a practical support and is a psycho-social support. Irish policy, funded through the NCCP, has identified transport as a significant support issue for people with cancer.
4 Findings and discussion

This chapter presents the key findings from the survey results (n=42), the interviews (n=7) and the participant observation report. It details the findings under three themes, which include the operational context; the benefits of the service and the future development of the service.

4.1 Operational context: Policy, procedures and practice

This section of the findings chapter details the results with respect to the operational aspects of the transport service. This relates to the transport policy in PH, the procedures around referrals, information provided to clients and the general practice and operation of collections and return journeys for clients.

The majority of survey respondents had heard about the transport service by word of mouth. The second largest per cent had heard directly from hospitals with 24% hearing from Purple House (PH).

![Diagram showing how people heard of the PH transport service](image)

When asked if they had seen a transport policy, 26% said yes with 43% saying no. Nearly a third of all respondents could not remember and this could be due to the stress of managing their cancer treatment. Notably, this figure of 43% could be due to the policy only strictly being enforced since December 2014.
Notably only 12% of those referred by hospital stated that the hospital has explained the details of the transport service. In comparison, 69% of those referred by PH had been spoken to about the transport service procedures. Ten per cent noted the driver explaining how the service worked and a further 10% stated that it was not explained at all.

Respondents were also asked to rate key aspects of the service including collections, pick-ups, accessibility of the service, and information on the service and making appointments Figure 5 shows that nearly three quarters of all respondents stated excellent to each aspect.
A key issue for people using the service was the friendliness and professionalism of the drivers. This was also acknowledged by the drivers as key aspects of the service. One driver stated:

If possible, I always try to meet my clients before driving them to hospital, instead of being a strange face turning up on their doorstep when they are already under stress. If I am able to meet them, I telephone to introduce myself and inform them of the type and colour of my car. It is also essential that the client is aware that you are not in a rush, so they are not worried about delaying you if they encounter any delays with their treatment.

Another interviewee stated that many people refer to the driver as a ‘new found friend’. The interviewee noted the importance of the experience the client gets and the relationship they build up with the driver.

Survey respondents spoke highly of the staff and drivers of PH and used words to describe them such as punctual, helpful, friendly, excellent, magnificent, easy to access, great, brilliant. Other stated that the drivers can’t do more for you as a client and how they have a great attitude and manners. The following comment\(^1\) captures the ethos of the transport service and the central role of the driver:

Since I started Volunteering for the centre, I have noticed a culture of empathy, kindness, friendliness, willingness to help, and a respect for people, all these attributes were displayed by [the driver] on the shadow day in question.

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\(^1\) Taken from participant observation research report, February 2015.

Purple House Cancer Support, Aubrey Court, Parnell Road, Bray, Co. Wicklow.
Tel: 01-2866966 Web: www.purplehouse.ie Email: info@purplehouse.ie
Overall, the staff and drivers featured regularly when respondents were asked to describe the best aspects of the transport service. Other key aspects mentioned included the door to door service, the convenience, the stress-free set-up and how accommodating PH is regarding the whole organisation of pick-ups and return journeys.

4.2 The value of the transport service to cancer patients: ‘He was more than just a driver, he became a friend’:

Fifty per cent of transport service users stated that they would have no alternative option if the transport service was not available. Other options available to people include family, public transport and friends but each of these options has associated stresses and complications, which can be avoided with the available option of the transport service provided by Purple House.

When asked how useful the service was, over three quarter of respondents stated extremely useful. Accessibility, homeliness of the Purple House Centre and general organisation of the transport service were all mentioned as being practical but significant elements of the transport service that clients praised as making their journey through treatment more manageable.

Findings from the participant observation aspect of the field research also draw attention to the very practical elements of a transport support service:

*I don’t think I realised how important it was to have people skills in Paul’s role as a driver. Firstly dealing with cancer must be so difficult, but the transport service Purple House Cancer support provides is invaluable in my opinion, making the journey to and from hospital a little bit more manageable. The thoughts of having to negotiate traffic jams, bus journeys, dart journeys, brings an added stress to the client which they don’t need under these circumstances.*
In addition to the practical aspects of the transport service that made people’s cancer journey so much more manageable, survey respondents mentioned finance as a key issue for them in accessing transport to and from treatment. This finding corresponds with established research in this area whereby research from the UK and other countries has highlighted the costs of travel experienced by patients and their families.

The emotional benefit of having the transport service available was also captured in the research. Depression, anxiety and general poor mental health are fast becoming identified as a part of the cancer journey and something that can be addressed through psycho-social supports. The positive impact on mental health ascertained from the field research highlights the role that a very practical service such as transport can play in promoting positive mental health. Again, this is in keeping with UK and international research, which has found substantial gains emotionally for cancer patients when transport support is available.

One interviewee stated that:

> Family members of clients who were unwell have come back on numerous occasions to say how happy they were with the service both logistically and emotional they received from the centre and its entire staff

The emotional benefit from the transport journey was also highlighted by an interviewee:

> In many ways ...both in a counselling role as there is evidence to say when you’re not looking at someone directly, like the driver focussing on the road, the client finds it easier to talk and open up, and they do this with our drivers, who then become friends as they open up and time goes by

As part of the participant observation for this research, a driver was accompanied on a journey. The following point from the observation report again shows how the transport service is more than just transport:

> I saw how empathetic he was with the client, and realised quite quickly that his role was much more than just a driving service to the hospital and is also a psychological support

The commitment, kindness and integrity of the drivers are repeated in each interview, with one driver stating:

> For me personally, I am quite happy to sit in a hospital for hours if necessary with a book and a cup of coffee while my client is receiving their treatment. This shows commitment and passion on the part of the driver

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2 see the literature review for a more detailed overview of research

Purple House Cancer Support, Aubrey Court, Parnell Road, Bray, Co. Wicklow.
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Another interviewee highlighted the medical benefits of a transport service for cancer patients during treatment:

_Gentlemen that have prostate cancer as part of their treatment they need to drink six glasses of water before their treatment in the hospital...This means taking buses to and from the hospital is not, ideal so the transport provided by the Purple House Centre is vital_

Specific groups were found to benefit from the transport service. For example, people living alone were identified as a vulnerable group when support is needed with transport to and from appointments. As one interviewee stated:

_Basically it is a lifeline for people living on their own_

This is a significant finding given that Census 2011 showed 392,000 people living on their own. The majority of those living alone, according to the Census, were single (56.3%). In addition, considering the number of lone parent households in Ireland, this also acts as a family support.

The value of the service to family members and family carers as an indirect form of respite was also shown in the research. One family carer, in a thank you note, wrote:

_I was able to have a badly needed rest, to help me to continue for the next week. It was just wonderful. I recognise the care and attention which was given to make it all work so well, matching the driver (a very nice man) up with my husband. Both of them enjoyed sport, they had great chats on the drive in and out from Blackrock. They became great friends to the end – It is a lovely memory for me now._

Another important finding was the role that drivers can play in communicating any developments for a client to Purple House. In this regard, drivers can be an important source of indirect support by raising awareness of an emerging issue for a client with Purple House such as the client becoming more ill during treatment or needing more home visits. One driver mentioned:

_Communication is knowledge and communication is discreet between the client and the driver...but if as a driver you feel concerned about a client or something they may have said, you can always relay this back to the Centre trained staff for assistance_

Another interviewee also highlighted this issue:

_For example, they may come back to say a client they have brought to the hospital may be in need of some counselling, the client may need help in finding out how to get a medical card, they may have a worry about another member of the family, or any other issues_

_Purple House Cancer Support, Aubrey Court, Parnell Road, Bray, Co. Wicklow. Tel: 01-2866966 Web: www.purplehouse.ie Email: info@purplehouse.ie_
4.3 Future developments

All respondents mentioned the benefit of developing an after hours service. Others mentioned the benefit of a second car and more stable, sustainable, funding for the transport service.

The amount of time demanded by the service was referenced by one interviewee:

*The transport service and requests for transport are getting busier as time goes on...It takes a huge amount of time from the centres point of view organizing and carrying out the transport service*

Interviewees specifically highlighted the financial strain on the transport service. Related to this was the lack of transport being provided by the HSE and other bodies. One interviewee remarked on not being able to provide enough transport for everyone that requires it.

Given the changing demographics in Ireland (see Census 2011); there is a growth in the number of clients from different ethnic backgrounds using the Purple House. This brings a demand for new skills for drivers and Purple House more generally. The growth in the number of people living alone and the growing elderly population means that demands for the transport service by specific social groups is growing. People living on low incomes access the transport service as a cancer diagnosis brings additional costs to a person and family. Given the austerity budgets since 2008, this number of people living on low incomes has also grown.

4.4 Conclusion

This chapter has highlighted findings from the research. Overall, the transport service was found to impact directly on the quality of life for people with cancer. The research found the operational aspects of the transport service were very well received by clients who referred to communication, journeys and drivers as all excellent. There were some issues identified regarding the referral process and communication of how the service operates. The transport service was found to be a practical support but also an emotional and financial support for clients. Future developments included the growing number and diversity of clients and the related demand on the transport service as well as the financial strain on the Purple House funding as there is no statutory funding source for this service.
5 Recommendations

This chapter presents a number of practical recommendations based on the research findings:

(1) Purple House (PH) to identify a sustainable funding source for the transport service.

PH need to meet with HSE and/or Department of Health Officials from the National Cancer Control Programme to discuss a possible funding source for this vital community-based cancer support transport service.

(2) PH to establish a referral policy for the service and communicate this policy to referral agents.

PH need to draft a referral policy and ensure that this policy is communicated to key personnel within the main referral agents such as hospitals, community health professionals and local service and information providers.

(3) PH to communicate the transport policy to all clients using the transport service.

PH has a transport policy. This policy needs to be given to every client on first referral or contact with PH transport service.

(4) PH to ensure that information on the service is communicated effectively to clients and wider community.

PH to consider drafting an information leaflet on the transport service that explains the basic referral process and overall operation of the service.

(5) PH to consider the possibility of incorporating a nominal cost for the transport service that is drafted in line with public transport and taxi costs.

PH to consider the possibility of asking clients to contribute according to their means. This could be organised on a very confidential basis and could be advertised as a service available to all regardless of income as it provided on a sliding scale.

(6) PH to monitor the positive mental health impact from the transport service.

Feedback from clients and families indicate that not only are their transport needs met but support and friendships develop with their drivers. PH needs to acknowledge the emotional and mental health outcomes from the transport service for clients. In doing so, PH should factor in transport support into needs assessments and care plans for clients. This needs to
be factored into outcomes and service evaluations as the transport service is more than just a practical support.

References


Appendices [available upon request]

1. Survey for completion by clients.
2. Interview questions.
3. Information leaflet for research participants.