

Introduction

Thank you for giving Macmillan Cancer Support the opportunity to provide evidence to the committee concerning the operation of the blue badge scheme in Wales. This written submission should be read alongside the evidence our colleague, Helen Powell, Macmillan Specialist Support Advisor: Benefits Advice Programme, will provide at the session for the 3rd sector scheduled for the 4th April.

Macmillan in Wales

More than 19,000 people are diagnosed with cancer every year in Wales (WCISU, 2017¹), a 10% rise over the past decade. There are now over 130,000 people living with and beyond cancer (4.5% of the population) and this number is expected to rise to 250,000 by 2030 (8% of the population).

Macmillan Cancer Support are committed to supporting our stakeholders, including the National Assembly for Wales, NHS Wales, Health Boards, Velindre NHS Trust, Welsh Government and other third sector organisations to improve care for people living with cancer across Wales.

Cancer can affect so many parts of a person's life and will impact on each individual in widely differing ways; the stresses far exceed the purely clinical and manifest themselves differently, whether physical, financial or emotional.

We invest heavily in advice services that help people better manage the impacts of cancer on a person's life and spent over £500k on our welfare benefits advice service in 2017 alone. It is an investment we are proud of, and one that is making a huge difference.

¹ Average cancer incidence (All malignancies excluding NMSC) in 2014 to 2015. Welsh Cancer Intelligence and Surveillance Unit, (2017) Incidence Extract <http://www.wcisuwales.nhs.uk/cancer-incidence-in-wales-1>

During 2018 our advice services in Wales helped secure £18.65million in welfare benefits payments to help thousands of people cope with the huge financial pressures caused by cancer, and money that finds its way into local economies. It is through this service that our Macmillan advisers support people with cancer who, due to the type of cancer, the treatment regimen or terminal diagnosis, have an impairment that means they are eligible to apply for a blue badge.

Macmillan Cancer Support aims to ensure that people with cancer are able to live life as fully as they can – whether it's physical, financial or emotional wellbeing. For many a car is essential for maintaining personal independence, accessing appointments and undertaking everyday activities.

The Blue Badge Scheme in Wales – Temporary qualification

Each case will be different, what matters to individual people will differ, but blue badges help people with cancer remain connected with family and friends, attend clinics, commute to work or visit the local shops.

We welcomed the expansion of the blue badge scheme in Wales in 2016 to provide temporary blue badges to people with cancer experiencing physical impairment. To inform this submission we consulted with our welfare benefits advisers across Wales – to better understand their experience of the blue badge scheme. We have attached the thoughts of those that responded in an annex and drawn on them throughout the following observations.

At a practical, operational perspective, we found that our advisers' experience of the temporary blue badge scheme across Wales to be largely positive. The support shown by local authorities has overall been commendable and allowed many people with cancer in Wales to acquire a temporary blue badge.

However, despite this largely positive experience, there is room for improvement. By drawing together the experience of advisers from across Wales we uncover significant, multi-faceted, variation across Wales - from the information provision about the scheme, the ways in which a person or adviser initially makes an application, to the processes and evidence used by a local authority to make a decision.

In 2016, Macmillan and the Welsh Government commissioned the second Wales Cancer Patient Experience Survey, and the results – published in 2017² show that only 48% of patients said they had been given information about how to get financial help or benefits, including blue badges.

Excluding those patients who said that they did not need written information, more than a quarter (27%) did not receive any written information about the type of cancer they had – including the effects of treatment - that this was easy to understand.

² Picker, Macmillan Cancer Support, (2017) Wales Cancer Patient Experience Survey.

“the info available on blue badge scheme is pretty poor especially around temporary conditions.”

Macmillan Adviser, West Wales

The 2013 Welsh Government advice for people concerning the rights and responsibilities of the scheme³ focuses more on the responsibilities of people on receipt of a blue badge, rather than offering public facing information on a person's rights and eligibility to a badge. The advice would benefit from being updated to reflect the different levels of eligibility, especially the newer temporary blue badge.

At key stages of their cancer journey, timely and appropriate information and advice can significantly reduce hardship, alleviate anxiety and stress, improve quality of life and help people make informed choices throughout their cancer journey – such as applying for a blue badge - to maintain mobility and independence. We believe that everyone diagnosed with cancer in Wales should have the opportunity to access high quality, consistent information, benefits advice and support at the point of diagnosis.

Once need and eligibility to apply for a temporary blue badge has been assessed by an adviser we have found variation in the routes to access and apply. There is variation between differing local authorities;

“Temporary forms for both RCT and Merthyr councils, but a general form only for Caerphilly.”

Macmillan Adviser, South Wales Valleys

and the digital gov.uk route offers another method of application. But we have found that in certain circumstances there is no guarantee that the application will be processed.

“Attempted to process a BB application off the gov.uk website, and when informed that the person had a terminal illness, the site, just said to contact Powys – without giving any other details.”

Macmillan Adviser, Mid-Wales

Switching to a fully digital application process is also a cause for uncertainty.

“Swansea LA have historically been good but changed to electronic version now through gov.uk website.”

Macmillan Adviser, South Wales West

³ Welsh Government, (2013) The Blue Badge scheme: rights and responsibilities in Wales
<https://beta.gov.wales/blue-badges-your-rights-and-responsibilities>

As far as the various routes to apply for a blue badge are concerned, experience is mixed. We are unsure of the true scale and scope of variation across Wales, including the rollout of the digital gov.uk application process. This is a critical area of inquiry for the Committee, equal access to the blue badge scheme – irrespective of condition – is vitally important, and would welcome a more thorough audit to better understand and evidence the issue.

Variation at the application stage is replicated at the processing stage, ahead of a decision being made. Local authorities are given wide discretion by the Welsh Government's guidance to set the method for determining applications. A variety of processes makes advising people with cancer, who may have received their diagnosis, treatment and follow-up care in different local authorities, more difficult as the criteria for decisions can differ from local authority to local authority. There is also an impact on the time of health service staff who are having to help provide evidence on behalf of a person's application.

“Advisor suggested whether they could accept an appointment card or consent form for Chemo, as this will give the side effects of the treatment and should evidence the impaired mobility. Time consuming for health staff to having to provide multiple letters for varying applications, and also impacts on advisor's time if they need to chase them for evidence.”

Macmillan Adviser, South Wales Valleys

“Some difficulties around getting appropriate medical evidence confirming the impairment will last at least 12 months – some badges being refused if say 6 – 12 months is mentioned – causes anxiety for health professionals to confirm this – another ask on their time too.”

Macmillan Adviser, South Wales West

Advisers have always built and developed good working relationships with decision making authorities for the benefit of their clients, but this degree of variation and levels of complexity complicates matters.

More efficient processes are possible; processes that better align to the health and social care integration, and “Once-for-Wales” agendas. Criteria and discretionary decision making could be developed and aligned to Regional Partnership Board boundaries, or at a larger, pan-Wales level. Were this the case we would expect existing best practice and known exemplars to inform wider improvements.

The Blue Badge Scheme in Wales – Terminal Illness

Our welfare benefits advisers also support people with a terminal diagnosis receive a blue badge. As with the temporary blue badge experience is largely positive, but improvements could be made.

Due to the nature of a terminal diagnosis, a person diagnosed to have six months or less to live, time is of vital importance. Terminal illness also includes a wide range of different illnesses and individual needs. People may have a single disease, like cancer, or a number of conditions.

Local authorities are given discretion by Welsh Government guidance to expediate applications, while we have anecdotal evidence of local authorities expediting the process, it is noted throughout the annex, we do not have a clear picture across Wales. We advise the Committee to better understand the extent of coverage. If in this instance coverage is not universal we would ask the Committee and Welsh Government to consider removing the discretionary element and making an expediated process mandatory in instances of terminal illness.

As with the temporary process we find considerable variation between local authorities across Wales. Presence of the DS1500 “special rules” form will trigger a blue badge in some areas,

“If person are special rules – very quick - send in the DS1500 to them and they issue a BB immediately”

Macmillan Adviser, North Wales

In other areas, evidence of an adviser, or health care professional will be enough,

“Advisor will sign terminal illness claims and verifies documents.”

Macmillan Adviser, South Wales Valleys

And there are instances where the expediated process relies on a mixture of both.

“Advisor can’t sign the form on the client’s behalf unless they tell the council the client is too ill, but can submit the DS1500, ID and evidence on their behalf.”

Macmillan Adviser, West Wales

Despite this degree of variation blue badges are being awarded at an expedited pace. However, this feels incidental rather than by deliberate design, due to the hard, diligent work of the people involved in the process. Working across local authorities and in some cases across health boards, this level of variation feels inefficient, and relies on advisers getting the right information to the right people at the right time. People with a terminal diagnosis, without advice or representation, would likely face a far more

daunting task navigating the system and securing a blue badge when time takes on even greater importance.
