Commercially sensitive information has been excluded from this document.
by cancer choice and control should help to secure the best outcomes. This is important for people with a cancer diagnosis and also for those with palliative care needs.

We welcome that the principles take into account the highly personal nature of providing care for an individual and acknowledge that by giving people informed choice and aspects of control, dignity and freedom of choice will be protected.

We are pleased to see the expertise of the carers recognised as an integral part of care delivery. Carers should be fully included in discussions about the cared-for person’s needs.

The success of Self-Directed Support will depend on the quality of information, advice and support available to people to make good choices. The Self-Directed Support Bill emphasises the duty of local authorities and NHS to make this happen and this is welcome.

A shift towards coherent Self-Directed Support practice will enhance the opportunity to promote better integration of care across health and social work and procure more effective use of shared resources across agency boundaries and budgets.

This last point is significant given existing and future pressures on budgets from changing demographic patterns of need and service capacity. Macmillan looks forward to working with all local authority partners and the NHS to maximise the potential application of Self-Directed Support to people affected by cancer and their carers.

**Q3 What are your views on the four options for self-directed support proposed in the Bill?**

We agree with the options proposed. It must be clear how the legislation will apply to the changing circumstances and care needs of people with cancer and other long term conditions. There should be an acknowledgement of the requirement for swift change which may be required in a relatively short timescale. This may be particularly problematic in end of life situations where 24 hour care is required within a short timescale. There should also be a provision for regular needs assessment to see if the individual budget is still appropriate for the person.

**Q4 Do you have any comment on the proposal that the self-directed support options should be available to children and their families, together with the proposal that the degree of control a child may have over the process should vary with age?**

No

**Q5. Are you satisfied with the provisions relating to the provision of information and advice, together with those concerning the support that**
should be offered to those who may have difficulty in making an informed decision?

The Self-Directed Support Bill sets out clearly the importance of access to good information and advice and stipulates the duty on local authorities to engage everyone who should be involved in decision making about Self-Directed Support. The explanatory and financial memoranda highlight the difficulty of predicting demands and capacity to deliver the quality of advice and support needed to implement Self-Directed Support. This needs to be tested more fully against the range of groups who might wish to secure access to Self-Directed Support options.

Q6 Are you satisfied that the method for modernising direct payments in the Bill will result in the change that the Government seeks?

Self-Directed Support is about more than Direct Payments. It is one way of securing better involvement and choice. The proposals on Direct Payments are reasonable. There will be much debate about when to apply charging/cost contributions. The key principle must be the ease of application for the individual service user. If this can be combined with an efficient administrative system for local authorities and providers then take-up will be enhanced.

Q7 Do you have any views on the provisions relating to adult carers?

It is important to recognise the unique needs of carers and their role in contributing to the wellbeing of those they support. A number of the Bill’s provisions will assist carers directly and this is welcome.

Q8 Do you agree with the approach taken by the Scottish Government not to place restrictions on who may be employed by an individual through the proposals in the Bill?

This part of the Self-Directed Support Bill is an ambitious step in reshaping the balance of shared responsibility between families and the state. Families and carers will welcome this shift offering them some compensation for the limitations their caring roles place upon their economic chances. Of course, it means that good advice and information around the interplay between earned income, taxation, and benefits has to be available.

Q9 Do you have any views on the assumptions and calculations contained in the Financial Memorandum?

The Financial Memorandum includes a presumption towards cost neutrality. Self-Directed Support of itself does not introduce new rights of entitlement to service or support. It changes the way support and services are arranged for people by giving them a direct voice and more control over the use of resources. It could be argued however that this vital shift towards ‘tailored support’ will encourage additional demand by ‘new groups’ and this will be on top of the acknowledged demographic changes that will lead to more need of social care and support.
Much of the reasoning for the Government’s cost expectations was drawn from studies which are fixed by historical patterns and use of Direct Payments. The numbers of service users and cases involved were rather limited. The initial allocation of resources announced by the Scottish Government reflects this bias.

People affected by physical and learning disabilities have always been the highest proportion of users of Direct Payments and other Self-Directed Support models of provision. The recognition that other groups should have access to Self-Directed Support is helpful.

It is Macmillan’s contention that the present resource allocation does not give proper weight to the reasonable expectation that people affected by cancer and many other long term conditions will meet the eligibility requirements of assessed community care needs and if service arrangements driven by Self-Directed Support developments are available, patients and their carers will be encouraged to pursue support and services. This will be the case if newer groups of users and carers can use individualised arrangements to change the context of strategic commissioning of services and support organisations with a proven track record of delivery and expertise in specialist fields.

It is often contended that Self-Directed Support or Direct Payments are best suited to people with stable conditions and circumstances, such as physical disability. Another ground for excluding people with variable conditions or terminal ill health is that Self-Directed Support /Direct Payments take time to work through. These are not just causes to exclude people and their carers affected by cancer. The investment in workforce development, training, and joint work with the NHS has to include an emphasis in widening access to Self-Directed Support to groups such as people affected by cancer.

Macmillan would also contend that the national resource allocation to deliver access to good quality information, support and advocacy services does not demonstrate a proper understanding of the costs required and the cover available across Scotland. Macmillan and other charities provide excellent information and support services which will be able to aid the delivery of Self-Directed Support.

Macmillan is keen to work with the Scottish Government, Cosla, ADSW and key local authority partners to study the implications of Self-Directed Support for people affected by cancer and their carers. Principally this would mean pilot work to estimate levels of care and support needs that would be eligible for Self-Directed Support approaches and estimates of the care and information costs involved to support users and carers in following Self-Directed Support options.

Our assumption would be that reviews of initial funding allocations could be influenced by additional research and experience of the outcomes for users and carers.
Q10 Are you satisfied in the assessments that have taken place in regard to these matters and the conclusions reached by the Scottish Government?

The general point should be noted that access to Self-Directed Support options will depend greatly on the corporate enthusiasm, skills, and informed awareness of assessment and care planning practitioners within local authorities. The Scottish Government has tried through conviction and resource allocations to highlight the importance of ensuring people are supported to exercise Self-Directed Support options.

Macmillan Cancer Support
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