

# Arthritis Care

## Response to Right to Control Consultation

Arthritis Care is the UK's leading user-led organisation benefiting people with arthritis. Our mission is to offer the nine million people with arthritis in the UK the information and support they need to make informed choices about managing their arthritis, to reach their potential in society and participate in their communities.

### Right to Control

Arthritis Care warmly welcomes the principles of the Right to Control and the Government's desire to ensure disabled people are able to make choices about how best to meet their needs.

People with arthritis make up the highest proportion of those claiming Disability Living Allowance (DLA) and Attendance Allowance (AA). Though these particular benefits are outside the remit of this consultation, they represent the advantages offered by unrestricted cash-benefits in helping people with arthritis manage aspects of their condition in a way that suits them. The numbers eligible for DLA and AA also reveal how many of people with arthritis will likely benefit from the changes outlined under Right to Control. It is important, therefore, that the outcome of this consultation seeks to fully meet their needs.

Independent living for people with long-term conditions needs to be seen in the context of self-management. The principles of self-management, pioneered in the UK by Arthritis Care, are about enabling people with arthritis to have the confidence, knowledge and support to take better control of their symptoms. Central to these principles is the acknowledgement that the people living with arthritis are best placed to understand how their condition affects them and what they need as a result. Expanding their ability to decide what services they access and how they access them will make an important contribution to strengthening self-management.

The Right to Control must support the need to provide the care services that people with arthritis may need on a day-to-day basis, but also support their ability to minimise the impact of their condition. If the most debilitating aspects of all forms of arthritis are not managed, this would seriously compromise the ability of a person to live independently and remain in work.

## **Meeting the needs of people with arthritis**

Funding included in the “trailblazer” site must support independent living or contribute to health outcomes which support independent living e.g. support to make adaptations to a person’s home or workplace; transport assistance, particularly for isolated communities; and assistance to help people exercise, which is a key measure in reducing the impact of arthritis.

As the consultation document acknowledges, good information is absolutely key to making this process tenable. Moving to a market model will inevitably stratify the number and nature of services and guiding people through this process will need to be carefully managed. Close working with organisations like Arthritis Care, which has a long history of providing information and engaging with the people that access our services, will be essential in making the transition and maintaining quality going forward.

The staff facilitating this process will need to have access to appropriate training to support people using services in trailblazer areas, in terms of not only understanding the processes and systems of the scheme but also the nature of conditions such as arthritis and the needs of people living with the condition. Feedback from people with arthritis often demonstrates that this awareness is low and can be a key obstacle to accessing key services and benefits.

Although we would welcome the variety in services and functions that could be offered by the trailblazer sites, there must be a consistency in both quality and what can be accessed. There is already a huge gap between the best-funded and worst-funded PCTs for musculoskeletal health services, and this should not be replicated

under schemes which could eventually qualify for inclusion in the Right to Control.

A wide marketing and awareness-raising campaign needs to accompany the roll-out of schemes at trailblazer sites. Many people with arthritis have told us that they are often unaware of the support that they are eligible for, and these gaps in knowledge should be addressed as the Right to Control is developed.

Measures to address the migration of people from existing services that may leave certain providers with low take-up should include support for peer groups and encouraging the sharing of information between users. While it will be extremely difficult to guarantee the viability of all existing services with the widening of choice, helping to ensure that all services are meeting the needs of disabled people could minimise the impact. Disabled people are best placed to make this judgement and should be supported to share their experiences.

Widening access to Occupational Therapists (OT) would further mitigate these issues. Taking advantage of the experience of OTs in ascribing care measures that have a more long-term outcome in mind will help to guide people with arthritis in their decision-making.

The consultation raises concerns over potential cost increases where a local authority may have previously purchased products in bulk, for equipment for example. The consultation suggests that service-users could negotiate discounts in groups. Some people with arthritis have told us that this could be unrealistic, particularly due to the additional strains and exhaustion that come from with living with their condition. On this basis, finding the energy and time to undertake such a negotiation could be a challenge to many people with arthritis. However this is addressed, people must not be worse off as a result of changes to funding arrangements.

As described earlier, good information is vital to supporting people with arthritis to exercise their right to control. Equally important will be support mechanisms to ensure that the process of accessing services is not obfuscated. Awareness of arthritis and the means to manage the condition is already low amongst the general public as well as health professionals, as most recently acknowledged by the National

Audit Office (NAO) in its report on services for people with rheumatoid arthritis. Without this knowledge and awareness, people with arthritis may not always be able to make informed choices about what services they access.

Support to exercise the right to control must, therefore, facilitate three steps: describing what is available; reviewing what will best meet a person's needs; and outlining where it can be accessed. This would require that awareness of arthritis amongst providers and people advising service-users be improved. There must also be robust systems for monitoring and incorporating service-user feedback.

Organisations such as Arthritis Care should again play a key role in managing this process, particularly in supporting peer groups and peer information.

The consultation asks what needs to be done to ensure disabled people and their organisations play a full part in the trailblazers. Opportunities to engage with planners and providers in trailblazer areas should be:

- open to everyone that wants to contribute;
- resourced to enable disabled people to participate e.g. money to cover costs of attending meetings/events; and
- with evidence to show what outcomes are achieved as a result of engagement.

Consultation must always begin at the earliest possible stage in developing the trailblazer sites and any future schemes. Getting the most from engagement activities such as these would necessitate an increase in resources to third sector organisations.

Agreeing an individual's support plan must be patient-led, with a clear point of contact that could, where appropriate, coordinate the process. It should also be incorporated or closely considered alongside any existing care plans relating to their healthcare. Existing frameworks such as the Musculoskeletal Services Framework, published by the Department of Health in 2006, and the recent NICE clinical guidelines for osteoarthritis and rheumatoid arthritis, already describe the need to take a "whole person" approach to care

planning. This sees healthcare converge with, for example, work support and social care support and recognises that services related to each area cannot occur in isolation. Furthermore, they describe the need for any support plan to be regularly assessed and be responsive to changing needs, particularly with variable and fluctuating conditions such as arthritis. Close consideration of these documents should be included when assessing the approach to agreeing a support plan.

## **Contact Arthritis Care**

To discuss any of the issues raised in this response, please contact

[personal details removed]