

# Coordinating Care

## What is it?

Coordination of care involves organising and sharing relevant information about a person's care between different services to avoid duplication and to achieve safer and more effective care.

Care coordination should take into account the whole family as well as a person's medical, mental health, school and work needs. It is important that everyone is able to access coordinated care regardless of diagnosis, individual circumstances and geographical location.

People living with rare conditions often have complex health needs that require support across multiple health services therefore having effective coordinated care is highly valued. However, most people do not receive this support and are responsible for coordinating their own care on top of managing their own condition.

## Genetic Alliance UK's Rare Experience 2020 report found that:

- **over 7 in 10 (71%)** respondents reported that the patient / carer is the one who coordinates the majority of care
- only **4 in 100** stated that they had 'a dedicated care coordinator'.

## For those who had a dedicated care coordinator

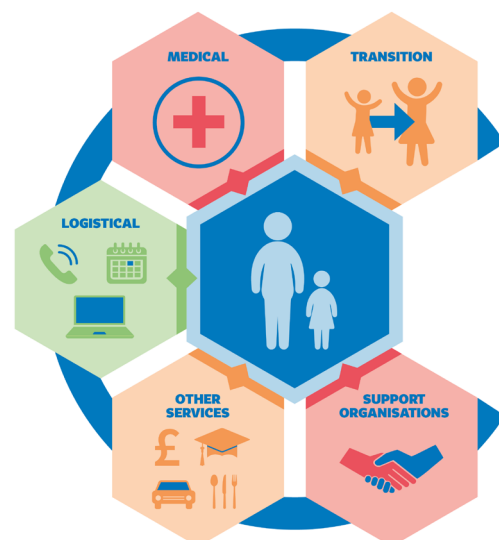
- **over 7 in 10 (71%)** felt that their care was effectively coordinated
- only **7 in 100** thought it was not.

## When the person themselves or their carer was the one who coordinated care

- around **a quarter (26%)** felt that this care was effectively coordinated
- **over half (58%)** thought it was not.

## The value of coordinated care

Genetic Alliance UK published **Coordinating Care: learning from the experiences of people living with rare conditions** in February 2023. The report looks at 8 experiences of care coordination from people with rare conditions and the health professionals connected to the services. The report shows the value of care coordination across 5 themes and the impact of its absence.



## Coordinating complex medical care

Many rare conditions are complex and require a multidisciplinary team to address them. Coordination between health professionals delivering care means more efficient and more effective treatment, leading to direct positive health outcomes

‘Many members of my support team consult with each other which makes a huge difference.’ (Respondent 262, 2020 Patient Experience Survey)

## Delivering well-organised logistical support

Families and clinicians value the administrative support that coordinated services bring. In its absence, people are ‘battling’, dealing with primary and emergency care, and filling in information gaps between care providers.

‘Annually we’ll travel to the hospital for a “full body MOT” that takes place over 2 days. It’s done in a coordinated way and it really feels like world class care.’ (Kez Hayat, 2023, Coordinating Care report)



## Assisting an effective transition from children’s services to adult services

Transitioning between paediatric and adult care takes place over a period of years and needs to be coordinated effectively.

Focused oversight and planning are necessary to ensure all aspects of care are transferred smoothly and effectively.



## Bridging the gap between healthcare and other services, such as education and benefits

Information exchange between healthcare providers and other services, such as schools and social care services, validates a person’s needs and reduces the burden of ‘battling’ that some families face in accessing appropriate support.



‘The real value of this coordinated approach is that we’re able to stretch beyond the healthcare system, particularly reaching into education settings which is very important ...’ (Prof Timothy Barrett, 2023, Coordinating Care report)

## Integrating support from rare condition charities and support groups

Individuals and families responsible for coordinating their own care often rely heavily on the information and support provided by third sector organisations. Support organisations can provide a vital role in the delivery of coordinated care. Genetic Alliance UK can support individuals and healthcare professionals to find support groups for their condition.

## Communication is key and improvements are always possible

No matter which part of the care journey, good communication is the fundamental basis for good coordination of care.

## Read our Coordinating Care report now