Effective coordination of a range of different services is a crucial aspect of care for people moving towards the end of life.

But achieving it can prove difficult.

In this film, we'll hear from people for whom communication between agencies has been less than perfect.

Sometimes you're going round and round in circles. You're not getting anywhere.

It's as if they're not listening to you.

But an innovative approach in the Northeast of England is hoping to show a new way forward.
South Tyne and Wear has set up a coordination centre which acts as a one-stop-shop for people moving towards the end of life.

So far, the results seem promising.

(woman) If there was one place that we could go to who could provide all of the information that we need, it would make a much different story for people, and a much better end of life for the family and for the patient.

Experts agree that coordination of care at the end of life is very important.

As you approach the end of life, you might suddenly experience a huge increase in the number
of professionals and practitioners

that you are engaging with.

Typically, having a key worker who coordinates

and who brings together that information

and shares it with the wider group of professionals is really crucial.

Good coordination of care

is about the strong relationships between the individual who's dying,

the staff, the family and the wider health and social care professionals.

It sets an environment of real security around the whole dying process.

Everyone knows what's happening.

Everyone knows
who is responsible for what.

Everyone knows who to go to when something hasn't happened.

That's really, really crucial. That's quite tricky.

Many people moving towards the end of life rely on a close carer or family member to help organise and coordinate their care.

Wendy supported her mother to access the services that enabled her to die at home after being diagnosed with cancer.

(Wendy) We were very fortunate.

We are quite an articulate family.
We knew how to access these services.

And I'm very well aware

that had we not had the knowledge
on how to access the services,

that those services
would not have been available to us.

My mother was very confused
at this stage.

She was receiving a lot of medication.

She wouldn't have been able,
had she been on her own,

to access the services
that we got for her.

Wendy was able to ensure that the health
and social care needs of her mother,

and the family as a whole, were met
with consistent and high-quality care.
We were involved with social services right from the beginning

to find out what care was available to my mother

and found out very quickly

that it wasn't just medical care that was available.

It was very useful to be able to call on other people other than medical people,
because sometimes the information and support you need isn't all medical.

I needed some assistance on what to do in the event of my mother's death,

which we knew was coming closer.

The social team that were allocated to us did give us that type of help.
Some people moving towards the end of life don't have a family member to act as coordinator.

It was people in this position which the charity Marie Curie Cancer Care had in mind when it devised its care coordination centre, based at its Newcastle hospice and part funded by NHS South of Tyne and Wear.

Coordination centre. Lorna speaking.

Heather McBeth is the centre manager.

(Heather) The role of the coordination centre is to put together care packages for patients who are palliative and end of life.
A patient will have a number of professionals involved in their care.

There'll be social workers.

There'll be nursing staff.

There'll be personal care providers.

There'll be domestic care providers.

What we need to ensure is that all of these professionals come together and communicate with each other and we are there to keep that communication going so that the patient is always at the heart of everything that we coordinate and do.
Today, Heather and her colleagues

are discussing how to bring together different services.

It's important, because social care needs can be overlooked

towards the end of life, when medical care can take precedence.

Her daughter actually works part time, so she needs some care
to cover the afternoons when the daughter's not in,
because she's bed-bound.

We need help and assistance with personal care,
toilet and medication prompt and things like that.

(voiceover) A lot of us have had personal experience
of trying to put together and coordinate

a package of care for a family member, a loved one.

It's difficult getting all the different elements together

and speaking to the right people.

(voiceover) So we can coordinate the whole package,

but we can keep everybody informed at every stage

as to who's coming out to deliver it, when they're coming out,

what they're going to actually be there to do.

The need for a coordination service is clear, listening to Claire's experience.
Claire is 38 and has a life-limiting condition.

In the past, she found dealing with a large number of health and social care professionals confusing and frustrating.

Over the years, I have met, well, not hundreds, but a lot of professionals, in care.

Sometimes, you're going round and round in circles.

You're not getting anywhere.

It's as if they're not listening to you.

You get a bit bamboozled.

"Where am I this week? Do I need to book an ambulance?"

It's just keeping on the ball.
I've got a diary
with every appointment in.

You get a bit lost. I think,
"What have I got to do next week?"

Claire has found the single point
of contact provided by Marie Curie
to be invaluable in coordinating
the services she needs.

The nurse that I see,
she's wonderful really.

She's helped me out
with a lot of things.

(voiceover) As in who can I contact
for this, that and the other?

We did have a social worker as such,
but she just seemed to be
writing notes all the time,
not taking in the information that either myself or my parents had.

The charity’s pilot scheme in South Tyne and Wear

provides a simple solution to what can be complex problems.

Problems which add to the burden of patients and families

at one of the most difficult times of life.

There are plans to extend the coordination service
to other parts of the country.

Families at end of life don’t just need health care,

they need social care as well to allow them to live what life they have left
to the best of their capability.
They need lots of kinds of support,

so all health and social care providers are important in delivering that care.

I can see that it will be recommended for replication throughout the area,

throughout the country.

Coordination is key to delivering high-quality care,

especially at end of life,

where patients and families don't want to repeat their story to lots of people.

We can bring it all together.