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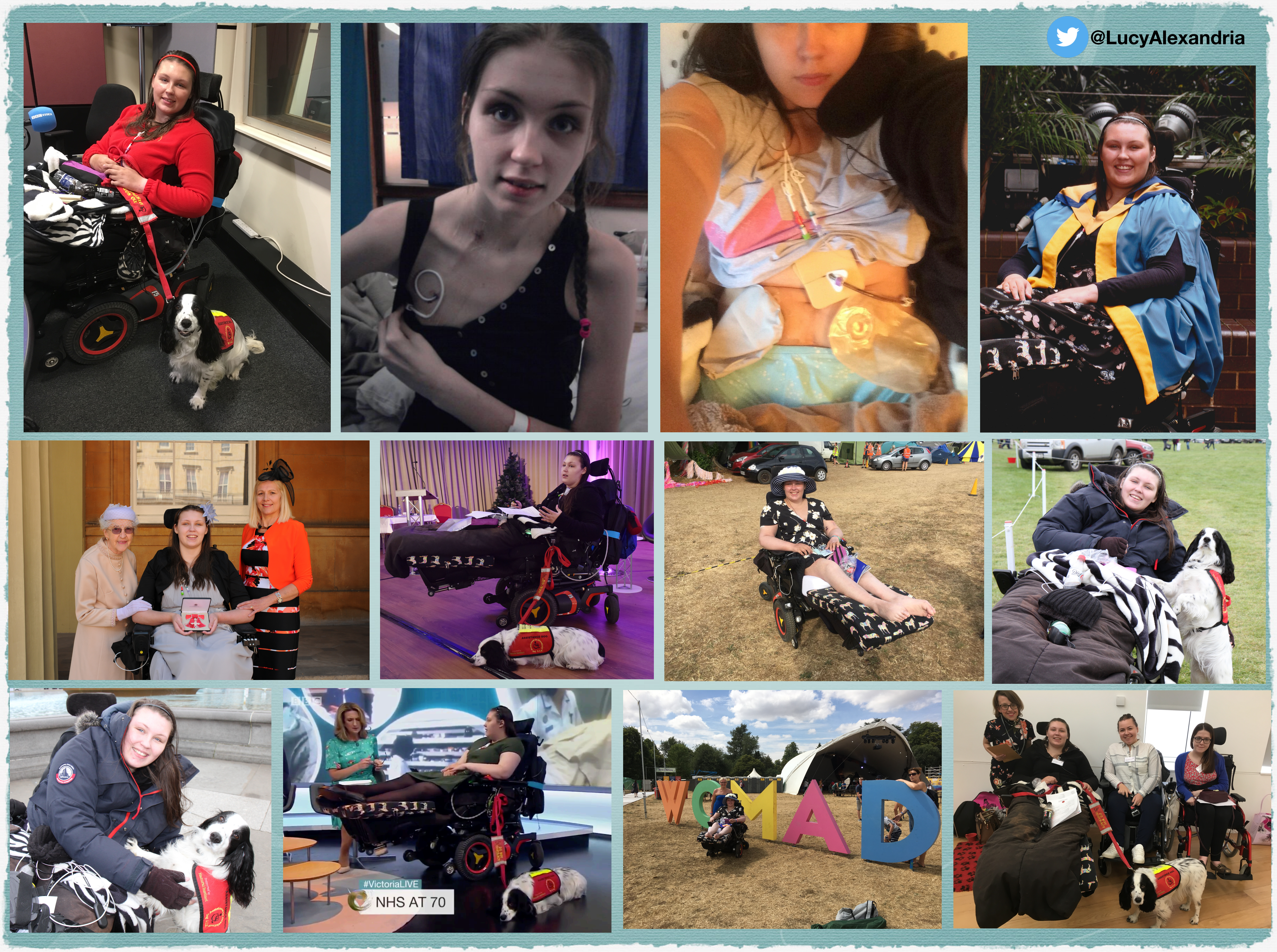
@LucyAlexandria

If you were the patient, what would good communication look like to you?

If you attend the workshop I am running later, we will be exploring this question in that session.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I have the most fantastic team of professionals involved in my care and have encountered many healthcare and allied professionals, most of whom have done a great job in communicating with me.

I hope you all can learn from my experiences of how these professionals have communicated with me.

These experiences form the basis of my talk today.

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#hello my name is...

teaches us all the power of introductions in improving care and patient experience

We also need to change the narrative from

"what's the matter with you?"

to

"what matters to you?"

One of the biggest conversations that I have had, one which no doubt worries all doctors and nurses most, is the conversation around end of life.

I am extremely fortunate that the conversations I’ve had about my condition being life-limiting, being given a prognosis and discussing my end of life wishes were done very well, very sensitively, very compassionately, and we were well supported.

My consultant told us my condition was going to shorten my lifespan, saying to me and my mother that my condition is going to keep getting worse, and that they'll do everything they can to keep me alive as long as possible, but one day my condition is going to end my life. We needed to prepare for the fact that I wasn't going to live a long life.

He was wonderful and stayed with us, answered our questions, checked we understood and explained that he'd continue doing everything he could to keep me alive and manage my condition to the best of our ability.

There was another conversation that was had about my survival, which, at the time, I was not party to. The consultant then explained that I wasn't expected to survive at all, I'd been left so long in such a severe state of malnutrition that they felt my body was too far gone and would reject nutrition, so TPN would fail.

I am glad I was not part of that conversation, as I feel I would've lost the hope I had for TPN keeping me alive and not fought as hard to survive. It's not that I didn't want to know - but that moment was not the right time.

Sometimes knowing when not to communicate something with a patient, is as important as communicating with them, and I am not saying to withhold information, but to ensure that the right information is given at the right time.

When doing my Advance Care Plan, I was asked about my wishes. It wasn't direct questions, rather she prompted the discussion, letting me talk as little or as much as I wanted to, not steering me in any direction, and making notes of things I said.

She used as few prompts as possible, with things such as if I'd ever thought about my end of life and had any thoughts or wishes I wanted to share, what mattered to me, had I ever thought about where I'd want to be and she also asked me had I ever thought about a time where I might not want any more treatment.

She listened, and sometimes she asked me to go back to something I had said to go into that into more detail about that issue or topic.

She also involved my mum in the conversation, with my permission, and mum also talked about this with us.

The conversation allowed me to specify what my end of life wishes were, it allowed me to grieve and come to terms with my own death and to plan for the future.

It also gave me and mum both the **permission**, as well as the **tools**, to talk openly about death and dying, it removed the taboo element, it gave us **confidence** and it gave us **language** to enable us to talk about it.

Giving people permission to talk about death is a huge thing, and it's your job as professionals to open the door to these conversations.

Also, the thing to remember, end of life conversations are as much about living as they are dying.

Such conversations should focus on wishes for life as well as wishes for death. They should help the person think about what they really want to do in the time they have left, what really matters to them, what conversations they need to have, plans they need to put in place and how they want their end of life to pan out and what life and quality of life means to them.

At the conversation, my nurse, Bev, asked me “So what do you want to do now? What matters to you?”. No one had ever really asked me that before. This transformed my life and was the catalyst that led to me starting the work I do today.

The next big end of life conversation we had revolved around my new prognosis at the age of 18 - since I'd already survived longer than expected.

My consultant visited us at the end of his shift, in his own time, and he spent over an hour with us. In this conversation he took my hand and he said to me and my mother "you know we've talked a lot about things getting worse. Unfortunately, we are not always going to be able to resolve issues when they arise, and we can't stop things from getting worse, your condition will continue to deteriorate and we cannot do anything to stop it. We don't know how much longer you will be able to survive these complications."

Mum asked "how long?". He said he didn't know for sure. So mum said "10 years? 5 years?" and he responded "5 years, at the most."

Now we know why they're called difficult conversations, but are they really difficult? With the right approach, the right person delivering it, the confidence, the compassion, the necessary time to give and the support in place for patient and also for you as the professional to deliver the conversation in the best way possible, we can remove the difficulty from the conversation.

My thoughts and tips:

Take your time. I know you're often pressed for time, but don't try to deliver a prognosis or difficult conversation in a hurry. It will give a bad experience for the patient or their parents/carers.

I am also a big believer of **being honest**. I truly believe knowledge is power, and we need to have the information to understand what's happening, to process our prognosis and to prepare for the future.

I also believe in there being **a right and a wrong time to deliver that information**.

There's never going to be a perfect time to tell someone they are dying, but there is definitely a bad time.

Try, when you talk about end of life, to ensure you open the door to open discussion of the subject for the patient and their family - not just in your visit, but in their lives overall.

Sometimes the sign of a good end of life conversation is when the professional does more listening than talking.

Good communication also requires understanding the impact of what you are saying on the patient and family.
It's also about listening and letting the patient speak.

It's about talking to them on the same level, respecting their experiences, giving them the platform to speak and ask questions, allowing them time to process, and adapting your approach to their unique needs.

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Good communication has a positive impact even when the news is bad,

and poor communication can have a negative impact even when the news is good.