

Is it Over?

What came after the LCP?

At the time of writing, the LCP is still in use, and there has not been a recorded decline in its usage, as 'phased out' might suggest.

But on July 14<sup>th</sup>, 2014 this will change and a new system will be enacted.

**The Leadership Alliance for the Care of Dying People (LACDP)** was set up to handle this transition. What this means is that the task of getting rid of the LCP and replacing it with (hopefully) something better, falls on them.

But there are some crucial things to note about the LACDP'S plan come that fateful day of July, 14<sup>th</sup>.

What is the plan of the LACDP?

Firstly, they don't plan on having the LCP replaced with another '**national tool**'.

The LCP was a **national tool**. It was used in every NHS trust by the end. It didn't start out this way (it started, not surprisingly, in Liverpool). But it eventually became a national tool when the Department of Health made it impossible for individual NHS hospital trusts to receive financing unless they used the LCP.

So come July 14<sup>th</sup> we won't be looking out for one program to check in that it's all working out fine, we'll be looking out for several.

So far, what programs exactly we'll be looking out for are unclear.

## MARIE CURIE

We know that one of the organisations working with the LACDP is Marie Curie, who developed the LCP alongside the Royal Liverpool University Hospital, and have since been the organisation behind selling and promoting the LCP.

So good to know they're back.

Of course, did they ever leave? It was Marie Curie that called for the review that ended the LCP. Supposedly in response to the media concerns that its 'high standards of excellence' weren't always being employed correctly. But it should be noted that even back in 2011 at the International LCP Conference in London, Tom Hughes Hallett, Chief Executive for Marie Curie Cancer Care, gave a talk entitled 'The Cost of Care – Can we afford End of Life Care?' where he walked on stage, announced he'd just got back from lunch with the Prime Minister, and talked about how the LCP was a step in the right direction for making end of life care affordable, but really we all needed to be dying at home to make it *really* affordable. Cut to 2014, Marie Curie now runs the Palliative Care Institute of Liverpool, where they plan on doing exactly this, with the full support of the LACDP.

Funny how these things work out...

**The only thing the LACDP will tell us for sure is that they're working on 'five priority areas' that will be finalised in July.**

1. The possibility that a person may die within the next few days or hours is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly.
2. Sensitive communication takes place between staff and the person who is dying, and those identified as important to them.
3. The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.
4. The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.
5. An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, coordinated and delivered with compassion.

And they sound great. But the LCP was full of great sounding guidelines, too.

The LCP required patients to be regularly monitored for any sign that they might improve and benefit from treatment to reverse the cause. But in many cases, they weren't checked on, and they weren't still being treated.

It also required doctors and nurses to communicate clearly and work in partnership with the patient and relatives. But in many cases, they weren't.

It stated that the LCP could only be used when a multidisciplinary team meeting was held, and all agreed the patient was in the last hours of life. But there were few if ever any meetings. And patients were being put on the LCP prematurely.

Nice sounding guidelines are great, but it's the law that will protect patients.

### **Will the Law change?**

Simply, No.

There has been no change in law to prevent the withdrawal of food and water from patients.

The LACDP endorses the same legalities as the LCP.

“Unless you have appointed somebody to be your Lasting Power of Attorney for health and welfare, they cannot legally make decisions on your behalf but they can, and should, receive explanations and be involved in discussions. A specific treatment can be legally refused (at the time, or in advance decisions by you) but specific treatment cannot be demanded.”

- Extract from Leadership Alliance for Care of Dying People ‘Engagement with patients, families, carers and professionals. October, 2013.

What this means is that, much like with the LCP, it will remain common practice to not consult relatives on decision making, and that it will continue to be possible to withdraw treatment from patients, which includes the withdrawal of water and food, as they are legally defined as ‘treatment’.

### Version 13 of the LCP

At its demise, the LCP was on version 12. The critics were used to a familiar pattern by now. Every time the papers caught on to concerns that the LCP was being used to hasten death in unnecessary and inhumane ways, a new version would be released, and for a while criticism would die down under the banner: “Everything’s OK now, there’s a new version, and it’s fixed everything.”

And then the criticism would come back.

Nothing was fixed.

Things were getting worse not better.

So when it was announced on the 13th of July, 2013 that the LCP would be phased out over the following six to twelve month, it marked a small victory, but not an overwhelmingly optimistic one.

The victory came in the form of recognition. Finally a number of the problems anti-groups and critics had long been campaigning against were being officially acknowledged. It was no longer the stuff of (accused) exaggerators and (supposed) conspiracy theorists. *More Care, Less Pathway*, the report which followed Neuberger's official review, spoke readily about issues such as: poor communication with relatives, the LCP's lack of condition specific practices, refusing food and drink to patients requesting them, the failure of the LCP to adhere to GMC guidance, and the excessive use of sedative medications on patients making it difficult for them to participate in decision-making.

But it's hard to be optimistic without real proof things were going to change, not after 12 versions of the same nightmare.

These are the key issues:

The **culture** of the NHS needed to be changed. It could no longer be normal to mistakenly put people who are not dying, or who time left, on a pathway that would see them a certain death within days. It could no longer be normal to not seek informed consent before making life or death decisions on behalf of a patient.

The **accountability** needed to change. No one at this time has ever been arrested for misuse of the LCP. The law protects the doctors and nurses, not the patients.

And finally the linchpin: **food and water** should never be withdrawn completely from patients. Food and water should be given with the comfort of the patient in mind, and should never be used to end life. It is a painful and inhumane death.

Unless these are the changes made, the LCP can be called 'LCP Version 13' or 'End of life Care Plan' (the name suggested in *More Care, Less Pathway*), or anything else, it makes no difference.