

Michael and Tom



A story of support, love and campaigning

In 1970's London Michael saw an advert for a gay social group on the London underground which led to a chance encounter with Tom. They have been together ever since. Here is their story.

When and how did you and your Tom meet?

Like a lot of young gay people in the 1970's I had to hide my sexual identity. There was no information out there like there is today, nowhere to go and be safe and socialise if you were gay, I didn't know of any openly gay pubs. If you picked up someone you could be arrested or lose your job, the public view of gay people was very negative. I saw a leaflet on the escalators of the tube about a meeting for gay people, I took the leaflet and went along. There was a meeting for the Gay Liberation Front, which turned out to be a safe space for gay people to socialise in. Once I was in the meeting I noticed that there were a couple of young chaps around my age sitting on a sofa together, and one chap that caught my eye, he was smiling down the sofa at me. This was Tom. He was my first love, my first ever boyfriend and we have been together ever since. We have been fortunate that we loved each other very much. I don't know what I would've done if I hadn't had taken that leaflet.



What has your life together been like?

As time went on more gay pubs opened so there was more options to socialise which is so important for gay people as they can experience such loss from their families. It felt like a hidden world we lived in. By the time the 80's arrived all of the progress we had made up until then ended with the AIDS epidemic. People went out less, and there was a huge backlash against gay people as a result. People in the general public talked about being divine intervention for Homosexuality being legalised. During this time, we went on a lot of holidays, we travelled around Europe. All of these experiences in the 80's gelled us together as couple. In the 90's we started going out again, seeing friends again. Then in 2003 Tom was diagnosed with HIV after her was assaulted. Tom was then diagnosed with Minor Cognitive impairment (MCI) Tom started having problem at work, the union got involved as we didn't know why he was treated badly by them, but it turns out that his job had become too complex for him due to his cognitive impairment, so he had to retire early on medical grounds. This was still years before Tom was then diagnosed with HIV-associated neurocognitive disorder (HAND)



When did you start caring for Tom?

I was still working, and Tom was doing all the washing, cooking tasks round the home, but things started happening at home like Tom would buy 20 hand soaps, or the spoons were going missing. We went out for dinner one evening and I asked Tom to order my dinner whilst I went to the toilet, and when the food arrived, he had only ordered his own, when I asked him where mine was he just looked blank at me. We were still not able to get support from dementia service until there was a diagnosis. I knew something was wrong, he once went missing one day then returned which was very scary so I spoke with our GP and then in 2016 we were given an appointment for an assessment. The shock of the diagnosis and finding out it was a terminal illness was huge, our lives was different from then on. Tom's diagnosis changed, he was diagnosed with progressive supranuclear palsy which creates all kinds of mobility and cognitive issues. I haven't heard him speak for 3 years, you do get used to the changes in your life, it happens over a long period of time it's a gradual degeneration. Its not an easy job being an unpaid Carer, its 24 hours a day looking after someone. A year ago I stopped working, and I became the manager of everything for me and Tom, I am not just his lover, friend and partner I am now his Carer, which is amazing, Carers do a great job as often a lot of the care is left to the Carer.

Has there been any barriers you both faced accessing support - Did services acknowledge your relationship? Were services respectful of your relationship?

I was involved with the Bring Out Dementia Project – We discussed the different experience LGBT+ people had when accessing support services. We would go appointments together and the professional would call Tom's name and he wouldn't answer, so I would speak up and answer for Tom and I would be questioned on who I was to Tom. This would not happen if it was a husband and wife. I have been asked in these situations if I have power

Of Attorney, there was always less assumption that we may be partners, it is often assumed that I am Tom's brother, or Tom is my dad not the obvious choice that we are partners. I know that professionals may feel that they need to ask but as a gay person who is already facing discrimination to then have to justify who I am as a Carer for my partner it is just insulting. It doesn't happen every time we go to appointments, but it has happened enough times. Gay couples may not feel they can be open with health professionals as they might not trust them or the services they work for due to bad experiences. I thought I had come out as gay in my 20's, but now I am a 65 year old man and as soon as I am in appointments or anywhere official support Tom I have to come out again. I am still coming out at 65. Straight people don't have to come out as straight all their lives, but I have to come out as gay every time I go to a heteronormative service. Its discrimination, lots of assumptions are made. It is a structural society issue, services are still geared towards heterosexual lives, services are heteronormative, and it needs to be tackled. Services and professionals need to be trained to work with all of the public. Most care workers and professionals are lovely, but sometimes they get it wrong and it can be hurtful.

Has there been any barriers to you being out to other carers or professionals?

After Tom got his diagnosis, I knew I needed support, so I started attending a support group in St Georges Hospital. I feel that our life as a gay couple can be different to straight couples. We'd been together the same amount of time as other couples, our relationship was loving and meaningful but we'd had a different experience to other couples in the group who may spend time talking about their grandchildren. But it had been the hardest year of my life, I was supporting Tom 24/7 and I was so tired. I started going to the group, there was 30 to 40 people in the group. A lot of the group did not know any gay people, it was one of the hardest things I have done, but the group facilitator was very supportive which made it easier, but it was still very hard being vulnerable and talking in front a group of straight people. I found it hard telling my mum and dad that I loved a man, so telling a group of straight strangers that I love a man was very hard, but I think most people in the group were so distracted by their own problems they are not really worried about your issues or sexuality. It shows that these services and groups are heterosexual ordinated, but I think it is very easy to resolve, services should tell LGBT+ people that they are welcome in their service, and staff should be trained to work with people as individuals, services can make activities in groups more diverse and less heteronormative. As time went on my confidence grew in the group, and I decided that I was going to say what I had to say not be off putted or ignored. I showed the group a video we had done about Tom's life which the

group wanted to see. I feel that for LGBT+ people going into heteronormative groups can be difficult so that is why I think it is so important to have LGBT+ Carers Groups, Age UK in Camden started a LGBT+ Dementia support group.

Have you any message for any LGBT+ Carers reading this?

LGBT+ Carers need to know that though the barriers for them accessing support is real, there are services and groups that will welcome you, even if they don't say that they welcome LGBT+ people. People accessing services may be offensive and ignorant, but those services are there for everyone. Barriers to accessing support sometimes can come from ourselves, we may not feel that we are welcome, but some of the support services have been so helpful, and I have learnt a lot from other Carers. I say go to any group you are invited to, even if they don't say they are LGBT+ friendly because it doesn't mean that the service is not. Other Carers can learn a lot about LGBT+ people from you as well, we had interest from other people in groups as there may be stereotypes that gay people just go out clubbing and can't actually be Carers. Just being visible in groups and services shows that we are all the same, it changes minds and attitudes you being there telling your story. I have found love and support in groups from other Carers. If the group or service is not meeting your needs then tell the professionals involved so they can adapt the service or group so it is inclusive.