## Independent Living

## Research Notes

(draft, 5 July 2019)

Born in southern England around 1928, Pamela La Fane developed rheumatoid arthritis from the age of nine years. Her mother and grandmother both worked in the theatre and home was mostly temporary digs and flats.

By 1940 aged about 13 years, she had began her hospital 'career' in Oxford, mostly in children's wards but at times in adults wards when beds were full.

Aged around 16 years in 1943 she was moved to another hospital, this time in London, for geriatrics. Here another patient told her, "the first ten years are the worst."

Later, aged 20 years she managed to get a free subscription for a freelance journalism course, and slowly managed to get paid small amounts for her published articles. She soon acquired a typewriter.

With the start of the NHS long-stay patients also were given an income for the first time, 12.5 pence a week then ("two shillings and six old pence"). Hospital staff began to get qualified. Before the NHS, "only the ward sisters were trained and qualified. The rest of the staff were called nursing assistants" and "walking patients" were expected to all sorts of jobs including feeding and washing other patients.

Pamela La Fane had now acquired a typewriter and one of her next articles was on her "gadgets" she had devised to feed herself, put on lipstick, and so on. She wrote later in her book:

"You dark horse," my physiotherapist greeted me some time later, "you didn't tell me you'd sent an article to our magazine." I didn't tell her that I'd been paid £2 for it either! (La Fane, 1981)

The years pass by: various operations, various hospitals, the occasional day trip out by a volunteer visitor. The medical system expected her to stay for life. She asked about alternatives. A council welfare officer told her, "the only places that look after the young chronic sick and disabled are the Cheshire Homes. And most of them are out in the country."

In 1966 Pamela La Fane noticed a letter in the New Statesman magazine, written by Marsh Dickson, a man with a disabled wife. They had been told he had to give up his job and care for her at home, or she had to go to the local geriatric hospital. He gave up his job, but feared what might happen to her if he became disabled too. He became the chair of National Campaign for the Young Chronic Sick, a lobby group for independent living.

Marsh Dickson persuaded Pamela La Fane to write a publicity leaflet for the campaign, but when the committee read it they offered it instead to the Guardian newspaper, and it was published on 23 December 1966. The pen name Michele Gilbert was used to avoid any reprisals. She only told two members of staff, both allies of hers.

This article led in turn to a mini-series of programmes on ITV in June 1968 in the 'Man Alive' schedule on Saturday nights.

It also led to a benefactor. There was a retired company director who ran a charity "which gives financial help to enable disabled people to live at home. And she wants to help you to live out of hospital," she was told by the campaign people.

Pamela La Fane continued to push for independence, seeking out one of the first electric wheelchairs (made in Wales), and pushing the hospital and council authorities for a flat that could be adapted to her needs.

On 15 July 1968 she finally left hospital to live in a flat, along with a volunteer helper who would receive rent-free housing plus a small allowance. Later, this was modified to be a rota of two volunteers.

Ten years later, she had the POSM (patient operated selector mechanism) system installed with its remote controls for household items such as opening curtains, switching on lights.

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The Guardian, 23 December 1966: Article Growing Up Geriatric, Michele Gilbert (Pamela La Fane) [not yet seen]

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The Guardian, 6 January 1967, Letters:

Sir.

Some of your readers may feel that the conditions mentioned in Michele Gilberts article "Growing up geriatric" must be exceptional.

In the experience of many of the people we have come in contact with this is not so and in some cases the improvements she mentions have hardly begun to materialise.

As we have pointed out to the Minister of Health and his colleagues, unless proper services and financial assistance are provided to keep the majority of these cases at home, where it is generally agreed they should be, this dreadful state of affairs will continue.

Organisations such as ours, started by the Chelsea Labour Party, DIG and others can batter at Ministry doors, but in the long run it is the pressure of an awakened social conscience that rebels at the present treatment of the Michele Gilberts, and the growing number of potential Michele Gilberts, that will achieve positive action. It is up to all of us.

Yours faithfully,

M. Dickson,Campaign ChairmanNational Campaign for the Young Chronic Sick.93 Marlborough Flats, Walton Street, London SW3.

The Observer, 2 June 1968, p22, TV listings:

Saturday 8 June 1968: 10.30pm (ITV London), 10.15pm (Regional ITV).

Campaigning for the young chronic sick: Actual title: 'A Life of Her Own,' first of a three-part series under the 'At a Time Like This' umbrella.

Concerns Pamela la Fane, prone solid with rheumatoid arthritis in a side ward of a geriatric hospital in South London since she was 16. She's now 40. The worst of It is, she's not "ill" and she's remarkably intelligent and buoyant on her own behalf.

The first programme is scenes from hospital life. Painful viewing. 'Man Alive' editor Desmond Wilcox first became interested over a year ago, when he read a piece she wrote in the Guardian. Since then, producer Richard Thomas has followed her case regularly. Murmured remarks about "intrusion" get the short answer that 'Man Alive' subjects invariably ring up afterwards to say they now feel much better. If they complain at all, it's cosmetically: "You photographed me when my tie wasn't straight." Wilcox: "We not only find the stories, but cure the cases."

In the second programme, on 13 June, viewers will see how Miss Fane campaigned to try to improve her circumstances and, on 20 June, whether or not she succeeded. "These programmes have been constructed as a series of cliff-hangers," says Wilcox, "and I don't see why one shouldn't." Valid new protest, or journalistic outrage?

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Sources here: book, newspaper, TV:

Marsh Dickson (1967), Letters, The Guardian [newspapers], 6 January
Pamela La Fane [as Michele Gilbert], (1966), Growing Up Geriatric, The Guardian [newspaper], 23 December. [not yet seen]
Pamela La Fane (1981), It's a Lovely Day, Outside [book].
Man Alive, ITV (1968), [TV programmes], 8 June, 13 June, 20 June.