

WINTER 1990

Frontline

A Magazine for Parents and Workers involved in Mental Handicap



PARENTS TAKE ACTION ON THE STREETS

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WHAT DAY IS IT ANYWAY ?

by
An Advocate

Since our first issue of FRONTLINE, the Clients' Page has been a forum for what people with mental handicap or special needs or learning difficulties have to say for themselves. But inevitably it is those who are most able who speak up. Who will speak for the person who has no speech?

Those people who are most dependent on the services provided for them, are least able to comment. In this article, someone else - an advocate - puts herself in their shoes and describes daily life as one severely handicapped person they know experiences it.

"A Paradise of real order, A tale of praise everyone"

C. Nolan, 1982. Sunburst of Dreams

Another day, another dollar, as the saying goes, but which one is it? I hear the footsteps coming down the hall. I've been lying awake for the last hour trying to figure out which day it is. I would have moved but my legs won't do that for me. I would have asked, but my tongue does not do it for me so I'll have to wait, - I think it's my turn now, and the door is opened up....

"Good morning, Patrick" as the big lady came over and lifted me out into my chair. I know a lot about her, but she does not know much about me.

"Oh, you've messed your bed again...." I know, it's not my fault, and anyway I had to lie in it for the last hour.

"Let's get you cleaned up." So they wheeled me off to the bathroom and got me out of my night clothes.

"In you go!" Oh! the bloody water's too hot!

The two staff talked about their families and the boss and the lousy pay they were getting for the job while they scrubbed and poured and just as I was getting used to the temperature they lifted me out, and pulled and turned me until I was dry. 'What day is it?' I wanted to ask. So down to breakfast I was taken; wheeled to the same spot for the last two years. I looked around the room to see fourteen of us at the same spot, probably wondering what day it is? Oh, by the way, my name is Patrick, I live here, this is a place for 'severely handicapped people'. It's strange, because I don't think I would be so severely handicapped if I wasn't here, - I

have dreams, you know. Anyway, I have been living (dying) here for the last two years, before this I lived with my family but then my mum got too old to lift me. (I weigh nine stone). My sister moved away to find work and I moved here. I wonder if they have the days figured out, perhaps I'll get some hints as time goes on. Breakfast comes. As usual it's porridge as it is everyday (no hints there). I can't move my hands to get the spoon in my mouth so I have to wait my turn again. I'm twenty two years of age and have a label of being profoundly mentally handicapped, but I do have dreams, you know. I dream of people helping me to live in an ordinary house like I used to, I dream of people talking to me, I dream of people listening to me, I can send messages. Here comes my helping hand, down goes the porridge! Breakfast done, it's off to the day centre. It's time for physio so I'm out now and on the mat, legs moved, manipulated.

"Good boy, Patrick." For god's sake, I'm twenty two.

"Lift them this way good boy, Patrick, good, lifting, lifting your legs." See what I mean about listening? I suppose I can't blame her; perhaps it's not my fault for not being understood. Ugh.

"Over on your belly give us a hand, Mary, to lift Patrick on his belly. Good boy, you're a clever boy today, Patrick, aren't you, isn't he a clever boy today, Mary!" Now it's time for my rest - back into the chair and pushed by the window. I sit there and stare into my hand. I'm very good at wasting time. I've been doing it a long time now. I really like it when somebody sits down and talks to me, tells me about things. I'd love to tell them about my dreams about the place I'd like to live, the friends I'd like to have, the things I'd like to do but I'm not very good at telling people things. I suppose they're not so hot on the listening but I can't blame them. The day passes on.

"We'll go for a walk". I heard a voice say. Oh, no, not down the drive again! So the wagon train begins. Coats on, scarves tightened and off we go all seven of us down the drive. Still no hints about what day it is. This wheelchair is getting really bumpy, I'd like a new one. We get to the gate. Fag break for the staff. I sit and wonder what's on the other side of the gate. Well, not wonder, 'coz some days - which, I'm not sure,

we go out on the
bus to see it. I
wonder
what it
would
be like
there
all
the



time

that's
another
one of y
dreams.

I'm getting
really sleepy
now, the medication

works. I don't mind it, it gives me a chance to dream some more - I'd like to see my mum a little more often, she only comes once a week. She sits and talks to me for a while, then talks to the staff, then goes home. I suppose I need to be here; I'm very difficult to lift and I sometimes have seizures. I don't like having seizures, it makes me feel funny and very confused when it finishes. I feel very lonely and would like somebody to be nice to me when a seizure is finished - sometimes it doesn't happen and I'm just put into my bed. There are lots of people in my life, well, about twenty five. Fourteen of these people can't talk either, I'm afraid. The rest, they talk to me sometimes but mostly about me. I would really like to have somebody to talk to me to show me places outside the gate and explain things to me. I'd tell them that too, if I could. Off we go again, up the avenue - what's that song 'I could walk up the avenue but I can't' - something like that!

Lunch time! There are usually some hints here! Today it's green beans, mashed potatoes and mince. Not bad. I remember the smell of my mother's cooking when I sat in the kitchen and watched her prepare the food. I haven't seen food being cooked for two years.

They don't think I'm interested but I am. If they would just wheel me in to the kitchen and watch my eyes they would see that I am interested. Lunch time is always so noisy here - people moving around and rushing. Here comes my helper, down with the grub. Loo time again, third time today. Wheeled in, lifted on. I wish people would not speak to each other while helping me on and off the loo as if I weren't there. It's bad enough, I don't blush when I'm embarrassed but I am, I have some dignity, I have wishes. Speaking when I'm helped on and off the loo is not a wish of mine, only that it should stop.

This afternoon should give me some hints about the day. Off we go to the day room for my programme - I'm wheeled to the table and the rings and stacker are placed in front of me:

"Come on, Patrick, put the rings on the stacker." "Well done Patrick." I didn't do anything. You lifted my hand.

They say I'm making great progress on this stacking rings. I wonder what I'll be doing when I'm finished. Perhaps this leads on to assembling electronic circuit boards. Somehow I doubt it. Or more stacking? So what! I think I have skills that I could use, I'm not sure yet what they are, but who's going to help me find out? I'm willing to help out, maybe even earn some money. It would be nice to earn some money and buy some things for my room. I would like to own a tape-recorder. I like listening to music (watch my eyes when the radio is on.) I would like to have some flowers in my bedroom, I like smelling nice flowers. I want curtains on the window so I don't have to lie awake when it gets bright. I would like to have carpet on the floor. It would be nice if I had money, I could have all these things. I don't own much at the moment, in fact, today I'm wearing 'company underwear' and this shirt that doesn't really fit. I feel quite silly with my bellybutton on view all day. When we go out in the bus I get my nice clothes put on, but I'm not sure what day we go out. The staff have disappeared so it must be tea break time or perhaps it's some more visitors. Lots of people come to see us here, look around, then disappear. Some people even say 'hello'. I wonder what they think of me when they look at me sitting here all twisted in my chair.... I wonder

will they see my hopes. I hope that someday they will see them.... perhaps they will come true.

But sure, I'm profoundly handicapped and maybe that's all they see, and I can't blame them for that. It's time for tea. I'm not hungry. I scream because I get fed up of stacking or going for tea when I'm not hungry. So now I'm trouble!

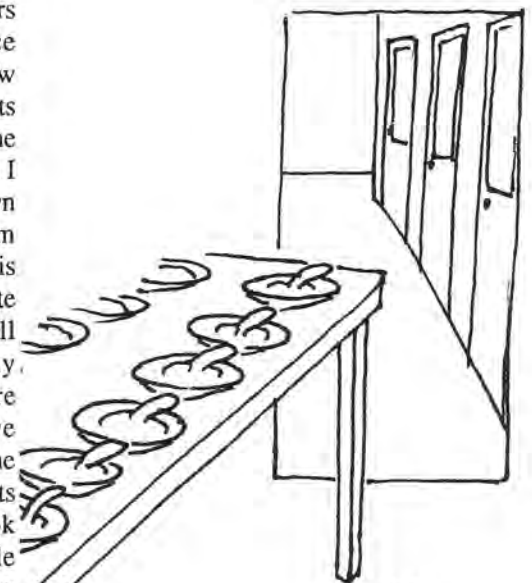
"Patrick is having one of his tantrums." Tantrum! - I'm just not hungry, that's all!

"Leave him, he usually settles down after a while - he's been doing a lot of this lately, we will have to have a meeting." Look, it's just that I'm not hungry. Now, why don't you just talk to me for a while instead of having a meeting and talking about me. Would be a lot simpler!

I can't help thinking about what the people who are there to help me are saying about me. I believe I have some value. I'm Patrick. If people value something they invest in it. This, perhaps, is my greatest fear, that people will not invest in me - invest their time by listening, invest their money to make my dreams happen. My hope is that because I know they care they might invest in a future for me which they would approve of for themselves.

Tea's gone, telly on. I don't understand it that much, but I'm wheeled in front of it all the same. Then the man says "Wednesday on Network 2 we have...." Aha! that's it! It's Wednesday. Funny, it doesn't feel like a Wednesday.

"Come, Patrick! Time for bed!"



D.S.