

The Child Who's Older than her Mother

UK TV documentary : 2003 : dir. James Routh : Uden Associates / Channel 5 : 25 min
prod: Patrick Uden : scr: : dir.ph.:

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Radio Times listing:

"A moving documentary about five-year old Hayley Okines [*who's four*], who was born with progenia – a rare ageing disease. By secondary school age her body will be like that of a 90-year old woman."

A title straight from "*The National Enquirer*" for what is actually a tactful but harrowing report on one British family coping bravely with a rare and terminal genetic defect. There are apparently no more than 40 known progenia sufferers alive in the world, and their families meet annually in California as a self-help group. Progenia loosely replicates the physical degeneration of the ageing process, so that the children look at best like one of Spielberg's "**CLOSE ENCOUNTERS**" E.T.s, and at worst like wizened little gnomes, their bodies racked by premature arthritis, rheumatism and associated conditions. The average life expectancy is 13, the children dying in most cases of heart failure or strokes.

The programme follows four-year old Hayley in her weekly round of medical tests, on the trip to America with her dad, and as she prepares excitedly for her first day at school. She seems a cheerful and good-natured soul, doting on her mother's new baby son, and enduring all the medical prodding and measuring without complaint. She looks forward to the day when she'll get better and be as tall as her teenage sister. Her working class parents both seem remarkably level-headed and philosophical about their appalling situation, to the extent that Hayley's dad recognises why medical science has invested little in researching his daughter's rare condition, when so many millions are suffering from AIDS.

One of my own sisters has spinabifida, and one of her daughters has Down's Syndrome, so on both counts I recognise something of the strains this family is being put through, yet it does seem an especially cruel caprice of nature (or god, if you prefer) to make a child wither and shrivel before its parents' eyes – to experience the pains of old age without ever experiencing the pleasures of adult life.

Several American "disease of the week" TV movies have dealt with teenagers expiring of "Methuselah syndrome", "accelerated decrepitude", and other approximations of the real condition, but none of them even remotely capture the distressing reality. It's particularly poignant to watch Hayley so eager for her first day at school when, in the context of her own

life expectancy, full time schooling is an absolute nonsense. Also, as with handicapped children of all kinds, we know there is great cruelty in the playground towards children who look in any way “odd”, and Hayley certainly does look “odd”. There must have been much agonising for her parents over the pros and cons of exposing her to that gauntlet of ignorance. The law says that all children must go to school – even those who will never reach adolescence – but the futility of that offers some small crumb of comfort to the parents: they perform the normal rituals of childhood, and “fitting in”, because there is nothing else to do.

Hayley herself, at four, only comprehends her condition in vague terms – her parents telling her just enough to prepare her for staring in the classroom, or the questioning of other children, but not enough to distress her needlessly. The programme-makers therefore do not speak to the child directly about her own feelings, and I was relieved to note that the images are left to tell their own tale, without heart-rending piano accompaniment, manipulative commentary, or emotional voyeurism – all the panoply of exploitative tricks documentary makers now use to wring the last drop of pathos from their subject matter. Channel 5 so often defaults to the lowest common denominator of audience appetite, it was refreshing to see them air a programme showing such commendable restraint.

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