

RESTRICTED - INVESTIGATION

ANNEX A

MACFARLANE TRUST: CHANGING NEEDS OF REGISTRANTS AND DEPENDANTS

Longer Term Survival

The position, outlook and expectations of registrants has changed significantly since the early 1990s:

Early 1990s

most adults employed

partners also employed

many boys and young bachelors

no expectation of long-term survival

in receipt of recent lump sum settlement payments (1990/91)

2000 and beyond

mostly unemployed

partners generally full-time carers

growing dependant families – few still live with parents

uncertain life expectancy

Additional Needs Identified by the Trust

Housing

- cost of setting up home and of moving
- cost of maintenance and adaptation
- unreliability of Disabled Facilities Grants

Complementary Therapies

- inconsistency of availability in the NHS

Extra costs of living with HIV a month)

- diet, fuel, clothing, bedding etc (est £400

Issues Arising from Co-Infection

- inconsistency of NHS treatment
- greater dependency on complementary therapies
- increased uncertainty of life expectancy
- added stress on families

Dependants

- no insurance or pensions provision
- partners generally unemployed (full-time carers)
- education of children (many suffering from trauma)
- post-bereavement trauma & poverty

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- | | | |
|---------------------------------|---|---|
| Constructive use of Time | - | mobility, communications, computers |
| Holidays | - | respite for carers and other dependants |