

Conference abstract

## Joining the dots: devising a supported self-help strategy to help pituitary patients integrate their medical care

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### Abstract

**Purpose:** The lack of integrated medical and psychosocial care limits—and potentially disables—pituitary patients. Providing resources specifically aimed at assisting patients in integrating their own care should lead to improved treatment experiences.

**Context:** The Pituitary Foundation (PF), a UK-based charity with 11,000 members, presents the best opportunity to understand the needs of this patient population. Part of the work of the PF is to respond to patient needs as identified by research and NHS guidelines (NICE Guidelines 2006)

**Data sources:** In 2005, PF commissioned research to identify the psychosocial needs of pituitary patients which explored their experiences through the process of diagnosis, treatment and ongoing condition management. The analysis identified that current medical care is fragmented and confusing for pituitary patients.

**Case description:** In response, PF has devised a two-part strategy:

1. Dissemination of research outcomes to the medical community; and
2. Production of a series of self-help booklets designed with the specific aim of enabling patients to negotiate the medical minefield.

**Discussion:** Changes to medical care take time to implement. Patient involvement in managing the demands of life long conditions is essential if full and individualised integration of care is to be achieved.

### Keywords

self care, patient needs, United Kingdom

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Presentation slides available from:

<http://www.integratedcarenetwork.org/Sweden2008/slides/01-02-jackson.ppt>