Alzheimer Scotland

Introduction

Alzheimer Scotland was asked by the Health & Sport Committee to facilitate a focus group with carers and people with dementia to gain their views on the regulation of care. Following the cancellation of the meeting, those due to attend were keen to ensure their experience was shared with the Committee. Unfortunately not everyone was able to contribute within the timescale.

The issues outlined below have been provided by some of those who were due to attend the focus group and callers to our Dementia Helpline. They relate both to care provider practices that the regulatory body should act upon, and issues with their own practices.

Quality of care

People with dementia are reliant upon relatives and friends to act on their behalf when there are problems with the quality and appropriateness of their care. A strong and robust regulatory body is essential to protect the welfare of those who do not have anyone to advocate on their behalf.

It is still problematic when there are family members involved in the person’s care. It can be difficult for relatives to know where to go for information. The language used by professionals involved in the persons care can also be unnecessarily complex.

Quality of care is considered to vary widely between different providers. A daughter was forced to move her mother on two occasions from different care homes until a third care home provided appropriate care.

Response to behaviours that challenge and medication

This is a particular concern; it was generally felt that there is little understanding or time taken to address the issues that care providers and others find challenging. Inappropriate prescribing of medication was closely linked to carers concerns that the root cause of behaviour that challenges was not being investigated.

Concern was expressed at a failure to properly investigate health concerns and also that there is no diagnosis of illness. People have been given medication that masks the underlying problem. Family members spoke of the cared for person being unable to communicate; however, once they had been taken off antipsychotic medication they had returned to being lucid and content.

Some relatives expressed the concern that they have felt compelled to agree to the cared for person being prescribed a sedative or antipsychotic drug, as otherwise the care package may be withdrawn.
It was considered that the dementia is often seen as the root cause of all ailments and that people are not treated as individuals.

Information and communication

The ability to question professionals is also a significant issue of concern. Relatives have felt powerless to challenge do not attempt resuscitation orders being put on the cared for person’s notes by a doctor visiting the care home. This has happened without the relatives being informed.

A family member reported being told by a care home manager that she asked too many questions of too many people; she was informed that questions should be directed to the manager and not any other staff.

Relatives expressed fears about complaining in care homes, as they felt the cared for person may experience poorer treatment as a result. This is a particular concern when a person has dementia, as they may not be listened to if they were to talk about mistreatment by staff.

Regulatory body

The regulatory body’s complaints process was felt overly complex and stressful. Having been through the process on one occasion, a family member felt reluctant to on a second occasion.

There was experience of the regulatory body not always following-up on their recommendations to care homes. Concern was also raised as why a service would remain operational when it had been deemed unsatisfactory by the regulator.

Paying for care and contracts

Although this is not of direct relevance to the focus of this inquiry, a number of issues have been raised that those contributing would like to share with the Committee. The system is considered inequitable; it was not thought clear or fair why some are paying for care and others are not.

Private care home owner had used contracts that had been judged unfair by Trading Standards using OFT guidance; however, as this is guidance only it was not legally enforceable.

The issue of private care home owners using self-funders to subsidise local authority funded residents was raised. Whilst this was not considered a new approach, the problem is considered to be getting worse, with one owner increasing fees by 140% over 4 years and another by 30% this year alone. This seems to be a particular issue in rural areas where the choice is much more limited.

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October 2011