

**Lives Interrupted:**

**Carers Voices**

***in Peterborough***

**Keith Sumner**

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Keith Sumner  
June 2010

## **About PCVS**

### **Peterborough Council for Voluntary Service**

Peterborough Council for Voluntary Service (PCVS) is a registered charity set up by local organisations in 1980 as both an umbrella and network organisation for the voluntary sector in Peterborough. Local charities, voluntary and community groups, self-help groups and statutory organisations access its services, as do members of the public.

PCVS also manages a number of projects at its offices in Peterborough. Many of which have been hosted by PCVS since their start. The organisation also responds to 'one off' projects and start-up projects with the view to enabling them to become independent over time. Our current projects include:

- Peterborough Carers (and Advocacy) Centre
- Peterborough Direct Payments
- Peterborough Volunteer Centre
- Peterborough Shopmobility

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#### **About the Author**

Keith Sumner has worked in health and social care across the public and independent sectors since the late 1980's. Trained as a social worker and social gerontologist, he has worked as a practitioner, a policy maker and senior manager. Throughout that time he continued to research and be published within these fields. He now works as an independent consultant ([www.ksaconsulting.org.uk](http://www.ksaconsulting.org.uk)). Keith has strong connections with the area, having lived and worked in and around Peterborough for many years. He has encountered the work of PCVS as both a commissioner of its services, and as a Carer, when his son was diagnosed with leukaemia in 1995.

## Foreword

Carers UK welcomes the publication of this book and the clear message it contains. A message that demands to be listened to.

It puts the voices of Carers at centre stage, and it is these voices that are the most powerful tool in fighting for change.

With the changing political and demographic Landscapes in the UK, issues for Carers have never been more important than at the present time.

Carers give so much to families and to society. Yet all too often have to pay a heavy price, with their health, their income and opportunities for realising their own ambitions.

I found their stories incredibly moving and believe that they tell a powerful story.

*Imelda Redmond*

Imelda Redmond CBE  
Chief Executive  
Carers UK



## Chapter 1

### Why Write this Book?

Many of us are *Carers*, or will have been at some point in our lives. For those who have not, there is every chance that we will one day find ourselves in such a role. Carers are not a group apart from the mainstream, they are our family, our relatives, our friends, they are us. As one Carer recently stated to me “...*we are ordinary people who find ourselves in extra-ordinary situations*”. It is still the case that many Carers remain hidden, anonymous to many of those around them – work colleagues, friends – and too often are virtually unsupported. Many do not even recognise themselves as Carers, a common barrier to seeking out the support that could make a major difference in their lives.

It is now fifteen years since the Carers (Services & Recognition) Act 1995 conferred the right upon Carers to receive an *assessment of their needs* separate to that undertaken for the person they care for. It is, however, still far from universal or common place for this to manifest itself in the form of a comprehensive range of local, accessible, services to support Carers, provided when they need it, where they need it and in a form that is adaptable and flexible enough to meet the particular needs of the Carer and those it is intended to support. Many Councils and their NHS partners around the country continue to perform at unacceptably low levels for those nationally reported *performance indicators* that relate to supporting Carers. Despite continuing criticism from government regulators, and pressure from Carers campaigning groups around the country, progress to close the considerable gap between the rhetoric of government policy intentions, and the reality of how support is experienced on the ground remains far too wide.

It would be untrue to say that no positive changes have taken place in recent years, but they are all too often modest and very hard won. The growing importance of giving a clear focus to tackling this issue nationally and at a local level cannot be overstated. It is the central purpose of this book to contribute to that effort. It also remains the case, that in tackling these issues, Carers are still not given the opportunity to take on a direct role in articulating their concerns and frustrations. In planning and carrying out the work to produce this book we wanted to address this by directly involving local Carers in sharing their thoughts and experiences of undertaking their caring roles. It is intended that this is shared with as wide an audience as possible to help promote a greater understanding of the quite profound impact being a Carer has had, and continues to exert, on their lives, and on the lives of those around them.

To this end, a series of interviews were arranged with thirteen local families, recording their stories and experiences in their own words. These Carers are drawn from across the generations, they talk about and share their thoughts on what it has been like for them, caring for a partner, a parent, a child, another family member or friend, often over many years. Those taking part are supporting people with a variety of disabilities, difficulties and illnesses, providing the reader with some insight into a range of experiences from across the life-course.

### What is it Hoped to Achieve?

The production and compilation of these conversations with Carers, and the accompanying material are intended to serve several functions, namely to:

- Be a valuable resource for local Carers, to assist people to identify issues relevant to their own lives through witnessing other Carers experiences in situations that may mirror or resonate with their own;
- Be used to provide Carers who may not be aware of potential sources of support with a bridge into accessing these local and national services;

- Be a catalyst to giving Carers - and PCVS on their behalf - a stronger voice, and a greater opportunity to gain the support they need to bring about positive change in locally available support services that would make a real difference to their lives and the lives of those they care for;
- Be a resource to increase understanding amongst the wider public of what it really means to care for and support someone, in terms of the personal impact of long-term disability or illness on those providing that support;
- Be a valuable resource for agencies across the public sector – particularly health, social care and housing services - through further informing and influencing those employed to help support Carers and to positively influence local policy and service development;
- Serve the same function amongst local employers across the public and private sectors, to encourage them to reflect this understanding in the development of employment practices that support Carers amongst their workforce;

This book will also provide PCVS with the opportunity to share these conversations on a much wider scale with partner organisations across the region to help to promote these messages. It is a critical time for Carers, both politically and in relation to the changing demographics across the UK. Every opportunity to raise awareness of their needs and rights should be taken.

I strongly believe that there is value in producing local publications to reach out to Carers, to organisations that represent them, and to engage those organisations charged with supporting them. It should be of assistance in stimulating debate and facilitating communication with those Councils and NHS commissioners who fund Carers services, namely those with the power and influence to make the greatest difference to Carers lives.