

# Palliative and end of life care



Demand for palliative and end of life care (P&EOLC) is set to increase rapidly as more people live longer and with multiple long-term health conditions. This POSTnote summarises the key components of P&EOLC and recent changes in policy. It also identifies inequalities and challenges in the provision of accessible P&EOLC services. The note reviews evidence on the impact of the COVID-19 pandemic on the provision of care and outlines key trends.

## Background

The World Health Organisation defines palliative care as an approach to improving the quality of life of people with a life-limiting illness and those close to them.<sup>1</sup> It includes symptom management and providing psychological, social and spiritual support.<sup>2</sup> Palliative care is typically started within two weeks before death<sup>3</sup> but it can start at any time. The NHS defines end of life care as a form of palliative care that can be received in the final year of life.<sup>4</sup> This POSTnote adopts these definitions. Palliative and end of life care (P&EOLC) aims to support people to live as well as possible and to die with dignity.<sup>4</sup> P&EOLC tends to be provided at home, in a care home, in a hospice or in hospital,<sup>5,6</sup> although it can also be provided in other settings such as prisons.<sup>7</sup> P&EOLC can be provided alongside other forms of specialist care, such as geriatric care.<sup>8</sup>

The UK's population is ageing<sup>9</sup> and it is estimated that by 2050, one in four people will be aged 65 years or over.<sup>10</sup> In England and Wales, by 2040, demand for palliative care is expected to increase by 25% to 47% due to complex multiple long term health conditions including cancer and dementia.<sup>11-13</sup> The non-profit organisation Sue Ryder estimates that to meet this demand, the total cost of hospice provision of palliative care

## Overview

- P&EOLC includes the management of physical symptoms such as pain, as well as social, psychological and spiritual support for someone with a life-limiting or terminal illness, and those close to them.
- Demand for P&EOLC is increasing as people live longer and with increasingly complex needs. The COVID-19 pandemic increased the demand for P&EOLC services and shifted provision outside of hospices.
- Research suggests that the quality of P&EOLC could be improved by early referral to palliative care services, providing services that support people to live and die according to their preferences, priorities and needs, and access to round-the-clock support.
- Stakeholders have called for improvements to P&EOLC including to service provision, service coordination, recruitment, workforce training, public education and funding.

services will average £947 million per year over the next ten years.<sup>14</sup> If trends continue, hospital-based palliative care costs could reach £4.8 billion by 2043.<sup>15</sup> Care homes are expected to become an increasingly important setting for palliative care.<sup>16,17</sup>

In the UK it is estimated that over 100,000 people that could benefit from palliative care die each year without receiving it.<sup>18</sup> The Health and Care Act 2022 includes a requirement for local Integrated Care Systems (ICSs) to provide palliative care services.<sup>19</sup> Academic and industry stakeholders, patients and carers have called for changes to the provision of P&EOLC. These include the provision of 24-hour, 7-days-a-week (24/7) specialist community palliative care support, education and communication skills training for health and social care professionals, and investment in community care to reduce unnecessary hospital admissions.<sup>15,17,20-25</sup>

This POSTnote focuses on adult P&EOLC in England and updates the 2014 [POSTnote 481 on P&EOLC](#). It summarises P&EOLC policies across the UK. It does not cover issues specific to P&EOLC for children or assisted dying (see [forthcoming POST work on Assisted dying](#)).

## Palliative and end of life care

Most people living with a life-limiting illness will require some form of palliative care (Box 1).<sup>26</sup> An individual can receive palliative care for any length of time, ranging from a few hours to several years.<sup>8,11,12</sup> Palliative care can occur alongside life-prolonging treatments such as chemotherapy.<sup>28</sup>

### Box 1: Generalist and specialist P&EOLC

- **Generalist care:** Most palliative care is provided by health care professionals for whom care of the dying is not the major focus of their work. For example General Practitioners (GPs), community nurses, hospital consultants, nurses and care home staff.<sup>29</sup> It focuses on day-to-day care and support.
- **Specialist Palliative Care (SPC):** This refers to services provided by multidisciplinary teams<sup>30</sup> that include consultants in palliative medicine, clinical nurse specialists in palliative care and specialist allied health professionals. SPC teams provide care in hospital, hospice and community settings and have a role in co-ordinating services, supporting generalist providers and providing bereavement support.<sup>31</sup>

## Key components of P&EOLC

Palliative care is a holistic approach that aims to manage symptoms and improve the quality of life and death for people with life limiting illnesses through symptomatic, psychological and spiritual support.<sup>4,32-35</sup>

### Management of symptoms

Palliative care has been associated with reduced symptom burden.<sup>29</sup> Common symptoms experienced by people with advanced illnesses are pain, fatigue, anorexia, shortness of breath and anxiety.<sup>36</sup> A range of medical interventions need to be tailored to the patient's needs (see [POSTnote 481](#)). Non-drug therapy includes rehabilitation, physical activity<sup>37,38</sup> and group exercise.<sup>39,40</sup> Obtaining prescription medications out-of-hours can be difficult, as can remembering to take them.<sup>41</sup>

### Social, psychological, and spiritual care

End of life care involves social, psychological, and spiritual care.<sup>42</sup> Patients with life-limiting illnesses can suffer emotional distress, depression and anxiety.<sup>43-47</sup> However these mental health needs can exceed the resources available at a local level.<sup>48</sup> A 2021 systematic review found indicators for monitoring and improving the quality of P&EOLC for people with dementia were often focused on the physical, rather than spiritual or cultural, aspects of care.<sup>49</sup> In its 2019 Long Term Plan the NHS committed to expand its offer of mental health services for different groups including people receiving SPC.<sup>50</sup>

### Advance Care Planning (ACP)

ACP is a process designed to give individuals and relatives the opportunity to discuss and document their values, goals, decisions and preferences for future personalised care<sup>51-54</sup> (see [POSTnote 481](#)). In 2022, six Universal Principles for ACP were published by 34 organisations including the NHS.<sup>55</sup> ACP aims to minimise unnecessary hospitalisations, avoid futile or unwanted treatments at the end of life and to maximise comfort.<sup>56-58</sup> Having ACP conversations whilst an individual still has mental capacity is important,<sup>59,60</sup> particularly for those diagnosed with

dementia.<sup>61-65</sup> During the COVID-19 pandemic, GPs undertook more ACP,<sup>66</sup> but ACP with residents in care homes reduced.<sup>67</sup>

Some studies show ACP can improve the quality of end of life care<sup>68</sup> and reduce stress, anxiety and depression in surviving relatives.<sup>69</sup> Some research indicates that ACP is associated with less time being spent in hospital in the last year of life, people dying in their place of choice and reduced hospital costs.<sup>70</sup> However, other research suggests that ACP has limited impact on improving communication between healthcare professionals, patients and those close to them, or people dying in their place of choice.<sup>71,72</sup> Reported challenges include:

- **Knowledge and competency:** staff report confusion about who has responsibility to initiate ACP conversations and issues around accessing ACP documentation.<sup>73-75</sup>
- **Consistency:** different documents and inconsistent terminology can be used to record P&EOLC wishes.<sup>75,76</sup>
- **Service user engagement:** a 2019 YouGov poll found 12% of 502 UK adults living with advanced or terminal illness have completed an Advance Decision to Refuse Treatment even though 43% know of treatments that they would like to refuse at the end of life.<sup>77</sup>
- **Public understanding and awareness:** a 2021 survey of 8077 adults across the UK by Marie Curie found over half of respondents did not know where to find information on ACP.<sup>78</sup>

## Managing and standardising care

Prior to 1 July 2022, Clinical Commissioning Groups (CCGs) were responsible for arranging P&EOLC services. The [Health and Care Act \(2022\)](#) introduced significant reforms to the organisation and provision of health and care services in England.<sup>79-81</sup> The Act established Integrated Care Boards (ICBs) to replace CCGs from July 2022, which aims to ensure a more consistent national approach and to support commissioners in prioritising P&EOLC.<sup>82</sup> ICBs now have a duty to commission and oversee health services including palliative care.<sup>19,79</sup>

NHS England funded the development of seven regional P&EOLC strategic clinical networks to support commissioners.<sup>83-86</sup> There is existing guidance for providers of P&EOLC on identifying needs, communication, coordination and decision making<sup>87</sup>, including from the National Institute for Health and Care Excellence<sup>88</sup> and the General Medical Council.<sup>89</sup> The Gold Standards Framework is a national accredited staff training programme in end of life care.<sup>90</sup> The Care Quality Commission (CQC) monitors, inspects and regulates health and adult social care in England<sup>91</sup>, including inspecting P&EOLC provided by community health services.<sup>92,93</sup>

The NHS Palliative and End of Life Care governance framework aims to "ensure personalised palliative and end of life care for people of all ages in all settings".<sup>94</sup> In May 2021 the Ambitions for Palliative and End of Life Care,<sup>95</sup> which describe what good P&EOLC looks like,<sup>96</sup> were updated to include fair access to care and maximising comfort and wellbeing.<sup>97</sup> Research examines indicators and frameworks to measure and optimise the quality of P&EOLC and geriatric care.<sup>49,98</sup> P&EOLC policies and definitions of terminal illness vary across the devolved nations (Box 2).

**Box 2: Strategic P&EOLC policies across the UK**

- **Wales:** Has a P&EOLC Delivery Plan<sup>99</sup> and an End of Life Care Implementation Board.<sup>100</sup> The Welsh Palliative Care Strategy included a funding formula based on population data.<sup>101</sup> A 12-month definition of terminal illness was adopted in April 2022, initially for income replacement benefits.<sup>102,103</sup>
- **Scotland:** Has a Strategic Framework for Action on P&EOLC.<sup>104</sup> In the Social Security (Scotland) Act 2018 the Scottish Government newly defined terminal illness<sup>105</sup>, replacing it with a broader non-time limited definition that has been used since July 2021.<sup>106</sup>
- **Northern Ireland:** Has a P&EOLC Strategy.<sup>107</sup> The Northern Ireland Executive adopted a 12-month definition of terminal illness from April 2022.<sup>108</sup>

**Access to benefits in England**

The Department for Work and Pensions provides fast-tracked access to the benefits system for people who are nearing the end of their lives through special benefit rules ("Special Rules"). Special Rules claims are fast-tracked and a face-to-face assessment is not required. No waiting period is applied, and the claimant is usually awarded the highest level of benefit ([Commons Briefing paper 8995](#)).<sup>104</sup> Since the [Social Security Act 1990](#), eligibility for the Special Rules has been defined as those who have been diagnosed with a progressive disease where their death is likely to occur within six months ("the six-month rule"). There have been several campaigns to reform this definition to improve benefits access, such as the 'scrap six months' campaign.<sup>109,110</sup> The UK Government announced that it would end the six-month prognosis requirement.<sup>102,111,112</sup> It introduced the [Social Security \(Special Rules for End of Life\) Bill](#) in May 2022 to extend eligibility to other disability benefits for those expected to live 12 months or less in England, Wales and Scotland.<sup>113–115</sup> This follows secondary legislation enacted from April 2022 to extend eligibility for the Special Rules in Universal Credit and Employment and Support Allowance.<sup>116</sup>

**Challenges and opportunities**

This section reviews the key challenges to providing high quality P&EOLC to all those who need it, as well as stakeholder suggestions for overcoming them.

**Impacts of the COVID-19 pandemic on P&EOLC**

The COVID-19 pandemic highlighted the importance of P&EOLC services as the demand for it increased.<sup>22,117,118</sup> More people with more complex needs required P&EOLC services.<sup>12,51,66,67,119–127</sup> here were major shifts in the place of care and death.<sup>12</sup> The proportion of people that died at home, in hospital and care homes increased whilst hospice deaths fell.<sup>15,128–133</sup> An international survey found that 48% of palliative care services experienced shortages of PPE, 40% experienced staff shortages and 24% experienced medicine shortages.<sup>134</sup> Challenges for the provision of P&EOLC during the pandemic included upskilling non-specialists to deliver P&EOLC, remote discussions with relatives and staff distress.<sup>51,119,127,129,135–139</sup>

Overall, evidence suggests that people experienced poorer end of life care during the pandemic, for example restrictions limiting family and friends visiting or saying goodbye.<sup>140</sup> Social distancing and visitor restrictions made it difficult to communicate with patients and their families and made

bereavement and grieving challenging.<sup>12,57,140–149</sup> Where resources and time were limited, evidence indicates that symptom management often took precedence over the more holistic aspects of P&EOLC.<sup>136</sup> A 2020 review by the Health Foundation found that health inequalities in England had increased,<sup>150</sup> partly due to the COVID-19 pandemic.<sup>151</sup> The pandemic exacerbated inequalities in accessing P&EOLC for minority ethnic groups<sup>152</sup> and visitor restrictions prevented families being able to fulfil religious and cultural practices.<sup>143,153</sup> The pandemic also exacerbated socioeconomic inequalities around place of death.<sup>154</sup> Evidence of the use of virtual communication technologies in SPC to communicate with patients and families is mixed.<sup>115,133–135</sup> The shift to remote consultations widened inequalities for those without the skills or access to digital technology and those with connectivity issues (see [POST rapid response on COVID-19 and the digital divide](#)).<sup>155,157</sup> Research suggests that virtual consultations improved access to palliative medicine for some patients that lip-read.<sup>158</sup>

**Funding**

In contrast to other health care services, around a third of funding for palliative care services is provided by the NHS, whilst the rest is funded through fundraising and donations.<sup>14,159,160</sup> The COVID-19 pandemic disrupted the fundraising activities of hospices, which put continuity of care at risk.<sup>15</sup> In response the Government made around £400 million available to hospices to increase capacity and to enable patients to be discharged from hospitals.<sup>161</sup> However Hospice UK argues that the financial sustainability of hospices is a concern.<sup>162</sup> A 2018 study showed there is great variation in the budget that local NHS bodies in England allocated to SPC.<sup>101</sup> Research by the think-tank IPPR estimates that people in the most deprived parts of England spend more time in hospital and receive £400 less investment per person in their last year of life than people in the least deprived areas.<sup>15</sup>

**Resources and provision of services**

Informal carers, often family members, are estimated to provide 75–90% of home-based care to people at the end of life.<sup>163</sup> Most people state they would prefer to die at home, which can shift some costs for care onto families and can be challenging for those experiencing poverty.<sup>163–167</sup> Stakeholders argue that more research is needed to understand the costs of P&EOLC including informal care.<sup>163,168–172</sup>

*Specialist palliative care*

According to the latest National Audit of Care at the End of Life in 2019/20, two thirds of hospitals in England and Wales lacked face-to-face SPC provision eight hours a day, seven days a week.<sup>173</sup> In some areas, hospice rapid-response teams provide SPC at home on a 24/7 basis.<sup>174</sup> Out-of-hours hospital admissions are common for people receiving end of life care due to symptom management issues and patient distress.<sup>175</sup> Unscheduled care for people in the last year of life is associated with older age, social deprivation, living in their own home and cancer.<sup>176</sup> Rates and lengths of unplanned hospital admissions increase as people with dementia approach the end of life.<sup>177</sup> Researchers argue that this highlights the need for improving end of life community care,<sup>178,179</sup> continuity of primary care and identification of palliative care needs.<sup>180,181</sup> Challenges for

community P&EOLC provision include time constraints, a lack of specialist knowledge and variable access to SPC.<sup>127,138,182–184</sup>

### Recruitment and training

Research shows that patient demand continues to outstrip the recruitment and retention of NHS staff.<sup>185–188</sup> A shortage of palliative care expertise and training, particularly in the social care and community settings, is a barrier to provision.<sup>189</sup> Over the next 10 years, 33% of palliative care consultants are likely to retire.<sup>190</sup> From August 2022 the palliative care curriculum for postgraduate doctors in training is set to change, requiring dual accreditation with internal medicine.<sup>191</sup> Some experts suggest this could inhibit the provision of 24/7 palliative care services across hospital, hospice, and community settings.<sup>192</sup> District Nurses provide generalist palliative care in the community.<sup>193–195</sup> In 2019 the Royal College of Nursing estimated that the number of NHS District Nurses reduced by almost 43% in ten years to around 4,000.<sup>196</sup>

Evidence suggests healthcare professionals need support and training to develop their competence and confidence in identifying, providing and communicating on P&EOLC.<sup>56,61,73,75,126,197–211</sup> The Ambitions Framework 2022 noted that all those providing P&EOLC should be aware of relevant legislation such as the Mental Capacity Act 2005 that seeks to ensure an individual approach and safeguard service users.<sup>95</sup>

A 2018 study showed training in palliative care for staff working in a homeless hostel improved knowledge, confidence, openness and reduced work-related stress.<sup>207</sup> Stakeholders suggest a managed, well-resourced and 'appropriately' funded shift to community-led care is needed to meet increasing demands for P&EOLC outside of hospitals,<sup>15,18</sup> including training more nurses and pharmacists to prescribe end-of-life medicines using electronic systems.<sup>197,212,213</sup>

### Accessibility

There is substantial evidence that inequalities in access to P&EOLC relate to many factors, including ethnicity, socio-economic deprivation, homelessness, imprisonment, learning disability, sexual orientation, age, gender identity, diagnosis, geographic location and socioeconomic status.<sup>7,21,51,63,163–165,214–230</sup> These barriers are exacerbated by uncertainty in prognosis, the needs of particular groups and a lack of public awareness of hospice services.<sup>221</sup> Older people and those with a non-cancer diagnosis are less likely to access SPC services.<sup>3,61,222,2317,63</sup> A 2018 study found that those without a cancer diagnosis, and those aged 75 and over, had a shorter length of time between referral to hospice SPC and death.<sup>224</sup> People living in the most deprived areas are less likely to receive SPC in the last year of life<sup>232</sup> and are more likely to rate their end of life care experiences as fair or poor.<sup>233</sup> A 2021 systematic review found that people with severe mental illness may not be accepted for end of life care by hospices or care homes if staff feel unequipped.<sup>234</sup>

Stakeholders call for inequalities in access to P&EOLC to be addressed.<sup>149,152,165,221,222</sup> Communication can be a barrier for accessing palliative care for those who do not have English as their dominant language.<sup>213</sup> In the UK there is a lower uptake of SPC services by minority ethnic groups, and services tend to be

accessed later than the White population.<sup>7</sup> This may be due to lack of awareness of services, lack of information in accessible formats, lack of confidence by clinicians, differing religious and cultural values, and the location of hospices.<sup>14,67,209,7,232</sup>

### Assessment of patient needs

It can be challenging for clinicians to determine if an individual has 12-months or less to live, particularly for non-cancer diagnoses<sup>63,112,236–238</sup>, due to prognostic uncertainties.<sup>20,73,199,239,240</sup> There are different ways to identify and assess palliative care needs such as through the use of tools and questionnaires.<sup>241–243</sup> The unpredictable course of non-cancer illnesses can inhibit the timely referral and receipt of P&EOLC, particularly for those diagnosed with dementia<sup>56,63,200,244</sup> and respiratory conditions.<sup>201</sup> Studies have found that earlier identification of P&EOLC needs in people with dementia may reduce unplanned hospital admissions.<sup>177,178,181,245</sup>

### Co-ordination

Some stakeholders note that information is not shared effectively between care providers<sup>246–248</sup> and that this can restrict patients' choices about their care<sup>189</sup> and inhibit out-of-hours staff and paramedics from reacting according to patients' information and wishes.<sup>202,249,250</sup> Few patients have an ACP that is available to medical teams during an unscheduled hospital admission.<sup>251</sup> Poor coordination between services<sup>63</sup> is a particular barrier for those who are homeless<sup>198,215</sup> or who have severe mental illness.<sup>252</sup>

Electronic Palliative Care Coordination Systems (EPaCCS) can be used to share end of life care patient information<sup>64</sup> and facilitate patients dying at their preferred place of death,<sup>253</sup> but the evidence base on its efficiency is underdeveloped.<sup>254,255</sup> In 2016 the CQC found that EPaCCS were not working effectively at a local level and it was unclear if the system supported the coordination of end of life care for people from different groups equally.<sup>63</sup> In a 2020 survey, the majority of prescribing nurses and pharmacists did not have access to an electronic prescribing system and had limited access to patient records.<sup>197</sup> In June 2022 the Professional Record Standards Body updated its standard for P&EOLC coordination.<sup>256</sup> Stakeholders have called for improved record-keeping and sharing.<sup>176,197,205,212</sup>

### Cultural acceptance and public perceptions

Attitudes and approaches to P&EOLC vary widely across religions and cultures.<sup>257–261</sup> Some academics suggest having a basic knowledge of world religions is a necessary skill in P&EOLC for clinicians.<sup>257,263</sup> Research identifies concerns from patients' family members that ACP would lead to treatment ending.<sup>184</sup> Greater knowledge of palliative care is associated with viewing it more positively.<sup>262</sup> A study concluded that unscheduled out-of-hours care for people in their last year of life might be reduced by improved public understanding of how to access the right care in a timely way.<sup>176</sup> Following the COVID-19 pandemic, social attitudes to death, dying and bereavement are changing.<sup>78,129</sup> The pandemic raised awareness of death and dying<sup>264</sup> and for some it was a catalyst for discussing their end of life needs.<sup>78,205,265,266</sup> Some stakeholders suggest that public education could reduce misperceptions of P&EOLC<sup>262,267</sup> and public health approaches could build capacity in communities.<sup>95</sup>

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