Chapter 5 Parents in Transition: Moving from Providing to Supporting Roles



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Introduction

Research examining parents' roles in their child's healthcare transition process has been conducted across a number of conditions of childhood onset including pulmonary disease. Findings identify common parental expectations, needs, challenges and concerns in supporting their children and interacting with health service professionals, with subtle differences in the family's experiences according to the impact of the underlying condition and its treatment [1]. This chapter draws on health and social science research in healthcare transition across a range of these long-term conditions to consider how parents and clinicians understand and experience changing parental roles. The chapter focuses on how parents undergo a parallel transition, from raising their child to parenting a young person, which requires subtle adjustments to their role, for example, from active to passive supervision of activities [1]. Crucially, parents remain an important and continuing resource for young people through the transition; both they and young people need coordinated attention and support from the clinical team during and after the transition process, albeit in qualitatively different ways [2].

Background

Transitional healthcare continues to be a policy priority for the growing number of children ageing with rare or complex health conditions and their care providers [3]. A successful transition is expected to produce a responsible, autonomous patient

who competently self-manages their condition and is ready to attend adult services in a timely fashion as the principal communicator with the adult team [4–6]. Clinicians therefore anticipate that during transition young people will take on 'a more empowered and active role as independent adult healthcare consumers' [4], seceding responsibility for their own healthcare from their parents' oversight.

Clinicians initially assumed that young people's needs during transition could be addressed solely by structural and procedural changes to healthcare systems and services [5], framing parents as people who need to be 'educated' to 'step back' and 'let go' [4]. An assumption that all elements of the young person's development (e.g. cognitive, emotional, physical and psychosocial) occurred at the same pace led to an anticipation of transition being a linear process. Clinicians' conceptualisation of parental care and involvement was largely binary; parents were essential in caring for all their child's needs, but a young person no longer required parental support. As such, clinicians supposed parents held an 'emeritus' carer status once their children had left paediatric care [7] and in early transition programmes ongoing parental input was largely positioned as problematic.

Perhaps as a result of clinicians' assumptions about them, parents worried that their child's transition to adult services would not allow them to be as involved in their care as they were previously [8]. Parents reported feeling ignored or sidelined at this point [9] with minimal clinical understanding of how they experienced the transition process in the context of their own needs. As Allen et al. [10] note, it was ironic that support for parents was often withdrawn at the very time when their needs for professional support and information were high. The small amount of research and service evaluation conducted at this time therefore neglected to capture a complete picture of young people and their families in transition [11], focusing instead on the 'experiences' of small samples, with little research including parents' perspectives [1, 12]. Even at the beginning of this century, there was scant evidence of the impact of healthcare transition on families [4], although there was an emerging recognition that families could become 'partners' in the transition process if they were sufficiently prepared.

Problematising the 'Family'

Parents provide support that all adolescents need to become more skilled at managing their own lives and together with the wider family are a key source of support for young people [13]. Rather than treading a short and linear path to independence in adulthood, young people tend to live for longer in their parental homes in most developed countries [13] and continue to experience a strong bond with their families after leaving home [14]. Even in the context of 'healthy' young people, the assumption of a smooth trajectory towards independence has ignored the individual and changing nature of parental relationships and their importance for young people [13], leading to the nature of relationships between young people and their families more generally being under-investigated [15]. However, regardless of clinical and

societal expectations of autonomy, individuality and independence [13], it is vital to consider the family structures and practices, including support, resources and contact, that each young person draws on through their transition. Of course, young people may live with one or more parents, in blended or extended families, experiencing different family values, communication styles and socio-economic status. In this chapter, acknowledging the heterogeneity of families, the term 'parent' is used to describe any adult that has significant responsibility for providing care and protection for a child or young person.

Early assumptions are now being surpassed by a growing acknowledgement that it is the family rather than the individual patient that is key to a successful transition to adult care. Just as an artificial distinction exists between 'child' and 'young person', so too exists an artificial distinction between parents caring and ending care for their child post-paediatric care; it is erroneous to think that families will 'let go', 'step back' or 'give up' [4] all the caring roles they enacted when their children were young. Strategies for improvements in the transition process increasingly recognise parents as an important component of successful transition through enabling their child to assume increasing responsibility for their health, providing a protective factor for their wellbeing and teaching their child skills necessary to self-manage their condition [11]. Transition should therefore be understood as a process involving an adaptation in care roles for both patients and parents. Views of both young people and their parents were considered in developing the UK's NICE guideline for improving care during transition [16], yet there is limited evidence to guide healthcare professionals as to what constitutes 'effective' parenting in transition and how they can support parents as they modify their roles [17], although early work provides many useful ideas.

The Nature of Paediatric Care and the Long-Term Condition

The philosophy of transition care is at odds to that of paediatric care, which works from a family systems approach to ensure that, as primary caregivers, parents are significantly involved in negotiating, advocating and making health-related decisions for their child [2]; for some parents their role will take a substantial portion of their time and form a significant part of their identity. In this environment, parental security is established through good working relationships with paediatric teams and from the continuity of their child's care that subsequently develops [12]. Over time, parents learn how to navigate the paediatric system, experience working in partnership with professionals, with their opinions largely being sought and welcome [6].

Two groups of young people essentially transition out of paediatric care: one with relatively stable and 'minimal' disease that can relatively easily leave behind their parents' involvement in their care routines and one that will have ongoing need for parental support through transition and into adult care, due to complex, progressive and unpredictable disease trajectories and health needs. The latter group, the

focus of this chapter, needs to not only maintain daily control of their health by mastering complex symptom management but also learn to communicate directly with health professionals about their symptoms and care needs and manage their clinic appointment schedules. There is a risk for parents of these young people to feel that their achievements made in paediatric care will be lost at transition, with little opportunity to build new relationships with clinicians and a sense of sorrow or abandonment at no longer being needed in the same way.

Historically, many parents (and their clinicians) delayed their child leaving paediatric care due to the absence of transition services and the lack of adult physicians trained to treat young people with complex conditions of childhood onset [4]. Cultural gaps in consulting styles between paediatric and adult clinicians were also slow to be addressed and communicated to families [12]. This reluctance to leave paediatric care may indeed have contributed to adult clinicians' perceptions of parents needing to 'let go' of their child and no longer be the decision-makers for their child's care [11].

Below I set out the key concerns that parents anticipate and experience at their child's move to transition care before focusing on their worries about the young person specifically.

What Are Parents' Key Concerns at the Time of Their Child's Transition?

Concerns About Post-paediatric Care Services

Limited awareness of the standard and availability of post-paediatric services continues to underlie many parents' feelings of being unprepared or unable to anticipate how their child's future needs will be met by healthcare services [1, 11]. For some, this perceived lack of preparation together with a lack of communication may lead to feelings of abandonment by healthcare professionals [1], concerns of whether transition will happen at the 'right time' for their child [12] and increasing uncertainty, ambivalence and reluctance to begin handing over care responsibilities to the young person [18].

For other parents, post-paediatric services are seen as complex, confusing, fragmented and procedural, leading to feelings of 'falling off a cliff' [19], their child being a 'number' on a 'conveyor belt', and perceptions of a lack of consistency in staff approaches [17]. For example, parents express concern that clinicians will neither realise that a young person is a new patient and give appropriate support nor establish relationships with families of young patients in transition [12, 20]. Others report a sense of disillusionment with health and social care systems that fail to meet the full range of families' complex needs [6, 21].

Through these concerns, parents have two key difficulties. First is anticipating the health-specific challenges ahead: both service-focused (such as where and from

whom future care will be delivered) and the quality of that care [8]. Second is protection of their child which is an issue of highest concern to parents [17], with threats arising not only from their health condition and uncertainty around future morbidity and mortality but also from more general worries about what is to come [2], including social and cultural issues such as sexual activity and employment opportunities. Transition care does not always respond to all the needs of young people, who also experience the broader and more typical transitions and anxieties during adolescence such as experiencing sexual relationships, managing self-confidence, leaving education, starting work or higher education and perhaps moving away from the family home. Here, clinicians should not only consider risks and uncertainties but also wider vulnerabilities to ensure a holistic approach [17].

Concerns About the Young Person

Many parents want to retain a sense of control of their child's health condition even when the young person with a rare or complex condition is an adult [12]. In that sense, they are not so unlike parents of 'healthy' young people who remain mindful of their child's ongoing health status and behaviour. Parents appear pivotal in developing their children's decision-making abilities, especially in challenging times [22]. Although a range of studies note the anxiety, uncertainty and fear that many parents experience at the time of their child's transition, these emotions may not commonly be expressed to healthcare professionals because parents are concerned about not being seen as over-advocating for their child or being 'difficult', as well as unfamiliarity with who and how they should express their concerns [21]. However parental anxiety can have a negative impact on the transfer of care tasks to the child and potentially lead to parents' overprotection of their child [18]. No relationship has yet been identified between parental anxieties and particular patient profiles [8]; thus developing more individualised patient transition protocols remains problematic.

Aware that their experience has been built over years, parents may also believe their child is unable to grasp and competently manage complex care in transition [23] or be ready to conduct all care tasks independently [4, 8]. Thus, parents may express concerns about a handover of care responsibility within a relatively short timeframe and at a challenging point in their child's life course. Perceived lack of adequate transition care may lead parents to continue as the care coordinator, assuming responsibility for communicating between different services and scheduling appointments [1]. Additionally, young people may decide not to seek healthcare during their adolescent years, there being a difference between capacity for independent action and making the choice to do so [10]. 'Control' or overprotection and conflict with young people over parents' 'constant checking' and questioning have been reported as children become more proficient at managing (or neglecting) their own care [1]. However, despite expressing ongoing worries and their need to plan,

parents also report working to adopt a balanced approach to their child's care that is not too restrictive or permissive [17].

It is relatively easy for parents to transfer routine and straightforward tasks, such as medication-taking, but harder to hand over responsibility for more complex tasks such as coordinating different care providers and decision-making for complex symptoms [17]. Parent's handing over of care roles is therefore complex and requires delicate support to achieve a balance. For instance, parents' desire to protect the young person's long-term wellbeing, for example, in nurturing their independence in self-management, can conflict with their need to protect their immediate health, especially for conditions that are unpredictable and potentially life-threatening [17] or where symptoms such as breathlessness mean parents need to access formal care on the young person's behalf [17, 23, 24].

For young people with rare conditions, care challenges also relate more widely to the lack of public understanding of what it is like to experience a particular condition and how this might impact how a young person experiences their daily life [23]. Parents' continuing concerns around the potential exclusion of their child from elements of social life have been noted [2], even when robust transition processes are in place. Parents of young people who are 'behind' in developing their social skills also need careful acknowledgement and support [17]. In these cases, parents' extended roles reflect quite reasonable responses to their child's social precarity [17].

Parents therefore remain key role models for their children, actively exposing them to opportunities where they can learn, enhance and display their self-care abilities in safe environments with increasing confidence [17]. Supporting families to cope with these very real worries appears to be a vital part of effective transition care [17]. The following section outlines some ideas for supporting parents.

Suggestions

Timing of Transition

Young people enter and move through transition services in relation to their own and their parents' changing roles and relationships. There are therefore no 'one size fits all' approach to successful healthcare transition and no evidence that young people's transition to self-management will continue at the same pace at home as in the clinic. Parents usually have a good understanding of when their child is ready to enter a transition programme, for example, through their increasing maturity, sense of responsibility, emotional stability and capacity to self-manage their condition [1], yet families still need time to adjust to the idea of transition. Planning discussions should begin at an early point in the process to give young people and their families in paediatric care time to adjust. As their child matures, parents do make alterations to their caring roles including their responsibilities, decision-making and healthcare

management [11]. Across a number of more recent studies, parents have been noted to perceive the transition towards their child's self-management as important, generally positive and something that young people are motivated to do, facilitated by parents gradually 'upskilling' the young person towards that goal [1]. The timing of healthcare transition therefore needs to be flexible, occurring when the young person and their parents feel it is appropriate and taking parents' concerns and suggestions into account [6]. Parents also need to be able to assure themselves that their child's transition programme is high-quality and comprehensive and has a similar intensity of care to the paediatric service the family is leaving behind while understanding that the style of care their child receives will be qualitatively different [4].

Providing Information

Parents receiving information at the same time as their child can help in numerous ways, for example, to enable them to feel prepared, informed, involved and reassured; to feel more secure when their child has left paediatric care; to help avoid misunderstandings about care intentions; and to facilitate future family and professional discussions [12]. Well-informed and confident parents are likely to be better equipped to pass on their knowledge and experience to support the young person's self-management skills [25]. Both preparatory and ongoing conversations and information are required [11], ensuring that transition care is not only in place but is visible to the family. General information about how transition and adult care is organised, including location, appointment format and clinic location, is essential [12]. However, information may be confusing and irrelevant, lack important detail or sometimes be too much in volume for parents to be able to filter what is immediately relevant to their child [2]. In communicating with young people and their parents, clinicians need to think not only about what information needs to be conveyed but also what form it will take [12], for example, a series of written plans that the young person and their parents can refer back to over time. Alongside this information, how their child will receive essential information such as what they should do if they become ill, or prepare for travelling, is also valued [12]. Parents' input into a transition plan that is then written for the young person may help to reassure the family that key information has not been forgotten [12].

A separate meeting for parents to meet the new clinicians should be an explicit part of the transition process preparation plan [8, 12], with the paediatric team introducing the patient and their family to the adult team [4]. Clinicians' collaboration with parents before the transition process begins can help establish their relationship with the new care team generally [12]; it is also helpful to identify a healthcare professional specifically responsible for providing care to the young person. For instance, a named coordinator, key worker or 'navigator' can be assigned to support the young person and their parents through the transition programme. This individual can identify and relay appropriate information at key time points, get to know

the family [2, 5], communicate with the wider healthcare team [6] and be a specific resource for the young person [5].

Enabling Network Support

Establishing a forum for parents and young people to share their experiences outside transition clinic appointments is an innovative way to support families. For example, peer support groups for young people with similar conditions could provide a network for their child to share their experiences and may help to allay parents' concerns that their child may be socially isolated [12]. Parental peer support groups in paediatric care can also enable parents to have a greater understanding of the extent of planning required for transition and the need for young people to begin to take ownership, developing a sense of belonging and mutual support and empowerment for parents and young people alike [21]. The shared experiences noted in research with parents of young people already in transition programmes with a range of underlying diagnoses suggest that non-disease-specific interventions for parents may help support their own role transition [1]. For example, parents may be able to gain new knowledge and became more future-oriented and active in preparing for transition [21] and their child's increasing responsibilities more generally. Peer parental support groups in transition can also enable parents to share their experiences, facilitate discussion of risky health behaviours and collectively problem-solve challenges such as how they could respond to the young person [12] and garner ideas for future planning [21]. Through parents meeting parents of older children, experiences of how other young people were able to take on more responsibility over time, and the benefits and challenges of this, can also be learned [12]. However, much peer support research to date in this context has involved small samples and pilot interventions, with high non-attendance rates at support groups due to competing demands on parents' time. Encouraging time-pressured parents to draw on a trusted network of supports outside their family such as teachers and peers at school may also help to support parents in their changing roles [1].

Communicating with Young People

It is vital to explain the rationale for developmentally appropriate transition care and have early and open discussions with parents about it – for example, where and when lone consultations with the young person will occur and who sets the pace and agenda of these [10]. Health professionals' belief that parents gradually lose their right to information about the young person has historically been embedded in their practice [24]. Similarly, many young people will anticipate attending transition clinic appointments alone but that their parents will continue to provide support and advice at home [10, 24]. Transition clinicians are required to simultaneously respect

the young person's autonomy and confidentiality while involving and supporting their parents so that they feel secure that their child's care needs are being met [12] and that they could meet their child's future needs if called upon to do so (e.g. in periods of acute illness). The extent of trust that parents have in their child's transition team underpins many of their beliefs about the appropriateness of maintaining the confidentiality of their child [26]. If the transition service does offer lone consultation, it is crucial to think about who sets the pace of this; early conversations with the young person and their parents about their preferred styles of consulting can help inform how consultations are patterned. Whatever the consulting arrangements, parents should continue to have access to practical advice and support regarding caring for their child [10], and be kept informed about issues they need to be aware of, within the limits of confidentiality. Parents may triangulate clinical advice with different sources of information and their own instinct [23]; talking to parents about other sources of ideas and how that might affect their ideas and experience of the transition process may help to avoid misunderstandings and stresses.

Confidential care is just as important for young people with a rare or complex condition as for those who are healthy [27]. Confidential consultations enable clinicians and patients to discuss more sensitive issues [4] and address young people's more typical health concerns. In the context of chronic illness, both parents and young people report healthcare professionals having good listening skills, being honest and maintaining confidentiality, as important [28]. Conversely, evidence also suggests a degree of parental involvement in care leads to improved health outcomes [1]. Parents identify both a range of benefits and harms of confidential care which may reflect a more general conflict associated with parenting any adolescent [29]. Complexity and controversy therefore surround lone consulting and confidentiality both for transition staff and parents, for example, what should be done if the young person has not attended their appointments and there is concern about their health, if parents believe young people are hiding vital concerns from clinicians or if the team senses that parents may be reading the young person's private clinic correspondence. The importance young people place on confidentiality may prevent them attending transition appointment if they sense a risk of their parents receiving or passing on their private information, yet complete exclusion of parents is difficult, especially if they believe their child is not coping [12].

In working to resolve concerns of confidentiality, it may be possible for clinicians to consider a longer appointment once a year for children around 12 years and over, the first part of which is a lone patient consultation, accompanied by provision of information about this format to young people and their parents [27]. In thinking about the limits of maintaining confidentiality, confidentiality may be better understood as a continuum than a binary [29], whereby three distinct options for disclosure outside the consultation are available on a spectrum between the two extremes of breaching and maintaining confidentiality: where the young person decides to disclose; where the professional discloses with permission of the young person; and where the professional breaks confidentiality with the young person's knowledge but not consent. Here, understanding the young person's issue and their developing autonomy can be considered. However, dilemmas of confidentiality involve

weighing multiple and conflicting risks with immediate and future harms, and professionals are unlikely to agree limits to confidentiality in all cases. Duncan et al. [29] list a range of strategies that can be used to minimise the potential for harm when managing confidentiality with young people: conducting thorough risk assessments; maintaining the therapeutic relationship; empowering the young person; supporting the whole family; and professional safety. This approach to conceptualising confidentiality highlights the complexity that needs to be worked through with young people and their parents.

Supporting the Parental Role

Parents should be understood as a resource for both the young person and healthcare team, with their expertise being acknowledged and taken into account in care planning [12]. Transition programmes must therefore include the family [4], recognising that parents are likely to have a continuing and adapting supportive role in providing care for the young person that might never be discontinued. Parental support appears to be a key factor in encouraging and facilitating young people to understand and build their ability to self-manage their condition [30] such that they become experts in their own care [1]. Being instrumental in their child's transition, parents remain active in preparing them for adult care, for example, by increasing the range and type of care tasks the young person undertakes and by moving to 'shared care' within the home [1]. It is useful therefore to consider parents as an integral part of the young person's supportive healthcare team and transition care for a young person as 'shared care' between the healthcare team and parents. Professional care needs to be directed towards both the young people and their parents in achieving this, developing transition programmes and service structures that recognise and respond to the continuing caring role played by parents [10], even as this role qualitatively changes as the young person grows older.

Parental involvement in transition care is a delicate and ongoing balance [29]. Ambiguity and uncertainty abound over what transition and adult care arrangements signify about parents' changed role, for example, their previous 'management' role may give way to a 'consultant' or supervisory one [1, 9, 24]. Working to allay parental anxieties will help parents feel supported in gradually handing over care tasks to their child. Identifying and addressing their concerns regarding risk, uncertainty and vulnerability can equip parents and young people to manage better through, for example, problem-solving, communication skills and role clarification [17]. Throughout the transition process, clinicians should regularly ask young people whether and how they would like to involve their parents in their care and in what capacity they should be communicated with [16]. While the young person is living in the family home and with the young person's permission, it is reasonable for clinicians to take advice from parents about their child and incorporate relevant points into ongoing transition care planning and to keep the parents broadly informed of plans when there are issues of which the family need to be aware [10].

Many of parents' initial concerns can be ameliorated if clinicians check in with parents once transition of care is underway [8].

Healthcare professionals are more likely to gain support from parents through building rapport and communicating the rationale and importance of care that appropriately addresses all aspects of the young person's wellbeing [17, 27]. However, just as care for the young person needs to be individualised, professionals' support for parents also needs to focus on their specific needs as their role in formal services and at-home shifts [12], understanding the stresses and challenges associated with changes at transition, including feelings of loss around the ending of the relationship with healthcare providers [11].

Working Towards Independence

Independence and autonomy are best understood as gradual, incremental and negotiated processes, with parents gradually transferring responsibility for self-care, in accordance with other increasing responsibilities, to their child, for example, in education and employment [1]. Parental care can be considered as a continuum or hierarchy of tasks and involvements; some are easily transferred as the child grows older (e.g. taking daily medication), whereas others (e.g. driving a young person to their appointments when this is the preferred option for the family) may be negotiated within the family and continue long into adulthood. Nevertheless, evidence consistently suggests transition is a complex and 'messy' process, with multiple transitions occurring for the young person and their family [10]. Clinicians should not assume that there will be an equivalent or smooth pace of transition to independence and autonomy in the home environment and should consider how cultural differences may influence the autonomy of young people in self-managing their condition. Most families work through their own processes of transferring care tasks, recognising differences in capacity and choice, and healthcare systems should be there to support them in this. Similarly, although 'independence' may apply to clinic visits and some care tasks, 'interdependence' may be a more realistic way of understanding a young person's care transition within the family home [31].

The process of young people assuming responsibility from their parents is part of a child's normal development but for young people with rare and complex conditions is often more challenging. As each child matures, parents make alterations to their caring roles including their responsibilities, decision-making and healthcare management [11]. Young people may also push back at parents for more control of their own care yet default back to them in times of acute illness. Roles and responsibilities therefore change differently over time as children become less reliant on their parents; some will be taken over gradually with parental supervision, for example, scheduling and ordering medication doses, where others may continue to be primarily held by parents, for example, advocating for a critically ill young person [24]. Others may be learnt in transition, for example, arranging clinic and referral appointments. Young people in private/insurance healthcare systems may need

extra parental support here, for example, in finding appropriate insurance policies and understanding reimbursement and associated bureaucratic elements [4]. For some tasks a young person will self-initiate taking responsibility, for others their parent may be explicit in transferring responsibility, or indeed the process of transferring responsibility for a care task may occur in response to an unforeseen event [32]. Role realignment is therefore generally renegotiated, with changes being instigated by both parents and young people [17].

In reality, full responsibility may be the aspiration, but this is less clear when parents remain involved in managing at least some aspects of the young person's care. Few explicit discussions about responsibilities or what 'full responsibility' might entail [32] typically occur, and due to a host of reasons, the young person may move backwards and forwards in taking on responsibilities. With development of a young person's independence and autonomy, the definition of a 'successful' selfmanagement may be negotiated. Here clinicians need to be aware that not complying with a treatment plan may be a young person's active choice [4], even though health outcomes may be adversely impacted [33]. Responsibility for care might also return to the parents if the young person disengages from transition process or needs respite care in periods of extreme illness or if end of life care is needed. Parents will struggle to catch up with immediate care needs they are expected to provide if they have had no involvement with professionals over many years. It is also important to be aware of a reverse protectionism that can occur in more complex and life-limiting conditions whereby the young person seeks to shield their parents from news about their deteriorating health state [24, 31].

Conclusion

Transition teams work to fit young people and their parents into an existing health-care system and service ethos, albeit a relatively new one. To facilitate their gradual handing over of responsibility for care tasks to their child and collaborate with healthcare professionals in efforts to transfer care tasks, parents need to be prepared for transition, informed and involved. Support strategies need to recognise the diversity of family experiences, goals and complex health conditions. Secure and consistent relationships between professionals, parents and young people appear likely to enable parents to be a steady resource and source of support.

Responsibility for care needs to be transferred incrementally at a reasonable pace, despite the change of venue and teams being swift. Parents and young people have many complex needs during healthcare transition that are not yet fully appreciated nor understood by clinicians and researchers [11]. The process of supporting both young people and their parents through transition is a balancing act, with teams having to navigate carefully between supporting both sets of needs [12]. Being aware that families have their own ways of managing transition away from the clinic, providing support and avoiding a prescriptive 'one size fits all' appears to offer a pragmatic way through the transition process.

More focused, higher-quality research is required with larger, more culturally diverse samples that take the unique context of each family into account [11]. Well-defined intervention studies, with evaluation of both effectiveness and family experiences, would aid understanding of how best to support families in transition. Additionally, more nuanced work focusing on how young people's condition-specific and developmental changes impact their parents as they grow older will also enable more specific guidance to be given.

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